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The insights gained from a portfolio of spiritual assessment tools used with hospitalised school-aged children to facilitate the delivery of spiritual care offered by the healthcare chaplain.

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Alister Bull - June 2012

## *A b s t r a c t*

A Spiritual Assessment Tool (SAT) for use with a child by a healthcare chaplain, requires a clear conceptual construct in order to convey a child's spiritual profile to other professionals. The design of the tool, allied to the manner in which a chaplain engages with a patient, allows a child to easily share information which can be interpreted in terms of this construct.

This thesis creates a new and accessible conceptual framework to describe the spirituality of children in a paediatric setting. It achieves this through the design and development of a portfolio of sorting cards and storyboards, referred to as a Spiritual Assessment Tool (SAT). The SAT encourages children to share information about their healthcare journey which is then interpreted in terms of the new framework. In addition, it identifies the competences required by a healthcare professional to obtain and interpret this information. In doing so, it necessarily discusses the wider implications of the theological insights which arise.

The research involved the filming of interviews conducted with children aged between 6 and 13 years old in an acute paediatric healthcare setting. During these interviews sorting cards depicting different aspects of the children's lives were used in conjunction with storyboards, in order to discover how the children described their lives while in hospital. The design of the SAT developed through two distinct stages before reaching a final model that achieved the goals of this thesis

In order to describe and share the information expressed with other healthcare staff, a framework was developed to enable interpretation of how a child constructs meaning. This framework required a terminology that could clearly communicate the complexities of how children understand the meaning of their lives in the context of the hospital setting. By engaging with child development theory and the data gathered from the interviews, the term "connectedness" was adopted to better encapsulate the conceptual construct of what had, in the past, been described as "childhood spirituality". The term draws four dimensions from the field of child development which help professionals to profile a child's perspective of their lives while in hospital: the momentum of connectedness; the awareness of connectedness; the resilience of connectedness; and the evaluative nature of connectedness. These dimensions take account of the contextual disruption experienced by the child and the way in which their level of development contributes to the perspective of their lives while in

hospital. The theological implications the concept of ‘connectedness’ and the methodology of its application underline the dynamics of the competences involved. These can be applied in integrated theological reflective practice.

The “Zone of Proximal Connectedness” (ZPC) is used to describe the space of an encounter between a healthcare professional and a paediatric patient when four features are present; hospitality, liminality, the significant other, and the co-construction of meaning. The ZPC forms the foundation for gathering information that serves as the basis for better spiritual care.

The research findings provide insight into the dynamics required for a healthcare chaplain to relate to a child and to engage in integrated theological reflective practice which relates to the ZPC. The nature of the encounter outlined in this thesis between an assessor and a child requires the quality of ‘mutuality’. The implications of mutuality reveal that in the Christian Faith our concept of God’s nature involves a greater sense of mutuality. The wider implications of this reflection for the Christian faith and our understanding of God, Jesus and the Church are identified as an area for future theological exploration.

## *Introduction*

This thesis seeks to discover what insights can be gained by applying a portfolio of spiritual assessment tools to hospitalised school-age children, in order to facilitate the delivery of spiritual care by the healthcare chaplain and the wider healthcare team.

This will involve:

- the provision of a clear professional language through which to articulate the complexities of a child's spirituality in a healthcare setting
- the design of a tool, ready for trial, which provides a child-centred assessment suitable for a healthcare setting
- the establishment of competency skills required by a healthcare chaplain to conduct such an assessment
- exploration of the theological implications of the research findings and how these inform a healthcare chaplain in a paediatric setting.

In order to achieve this, it is first necessary to understand what is involved in the delivery of Spiritual Care<sup>1</sup> as defined by the NHS Scotland and the Scottish government. Also identifying the locus of the discipline at the start of this thesis enables the reader to understand why theology has been used to gain insight into a healthcare context.

Chapter 1 explores the struggle to establish what is meant by the term "spiritual" with reference to the concept of "spirituality". It provides an overview of current thinking, highlighting the key difficulties in existing concepts of spirituality and presenting an assessment of previous attempts by those who work within healthcare to create a new conceptualisation of spirituality. The chapter establishes an argument for the need to construct and apply an accessible concept of spirituality that provides an appropriate, interpretative framework for a healthcare chaplain to make assessments in a healthcare setting.

Chapter 2 discusses in detail the criteria required for an effective interpretative assessment framework to encompass the needs of children at different developmental stages. Insights are

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<sup>1</sup> Spiritual care is a requirement by the Scottish government legislation detailed in HDL (2002) 76 Spiritual Care in NHSScotland and updated in CEL (2008) 49 – Spiritual Care

drawn from Piaget's Cognitive Theory, Erikson's Social Development Theory, Fowler's Faith Development Theory, Bronfenbrenner's Bio-Ecological Theory and Vygotski's Social Cultural Theory in order to establish the structure of a framework which accommodates different childhood stages. It is hoped that drawing from these theories will allow for the development of an interpretative framework which can assist in the spiritual assessment of a hospitalised child. It is proposed that a methodology involving play and storytelling may enable children to share what is most meaningful to them.

Chapter 3 develops this methodology further through deeper exploration of Bronfenbrenner's Bio-Ecological Theory and the Social Cultural Theory of Vygotski. Drawing from Myers' application of Ritual Process Theory enhances the understanding of how children construct meaning at different stages of development, and how these theories relate to the findings from the Spiritual Assessment Tool (SAT). This provides a theoretical basis for a critical overview of how play and storytelling is used within the healthcare context for care, research and psychotherapy. The research of Susan Engel (a developmental psychologist in storytelling) offers specific insights as to how play and storytelling may allow for a point of connection to be made with a child, and examines how theory moves into practice. We are left with the question: Is such a methodology currently used in an appropriate way in the spiritual assessment of paediatric patients? The purpose of assessment in the NHS is to ensure that healthcare staff offer the most appropriate care. The only multidisciplinary assessment of patient needs in the UK which takes spirituality into account is the "Liverpool Care Pathway"<sup>2</sup> which contains a comprehensive assessment of end of life care for adults.

Chapter 4 categorises the types of SAT that healthcare professionals have previously employed, and currently employ, to gather and handle patient information. Current techniques for the application of Spiritual Assessment Tools (SATs) used in North America and elsewhere have been examined and some practitioners, such as chaplains and social workers, have attempted to use Spiritual Assessment Tools to explore spirituality in adults. However, as there is no shared understanding of what spirituality means, it is not always clear

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<sup>2</sup> This is the opening statement on the Marie Curie Palliative Care Institute – Liverpool describing its purpose (Cited on 26.6.12 - <http://www.mcpcil.org.uk/liverpool-care-pathway/>) "The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life. It is a means to transfer the best quality for care of the dying from the hospice movement into other clinical areas, so that wherever the person is dying there can be an equitable model of care. The LCP has been implemented into hospitals, care homes, in the individuals own home / community and into the hospice. The LCP is not the answer to all our needs for care of the dying but is a step in the right direction. It is recommended as a best practice model, most recently, by the Department of Health in the UK."

what such tools are ‘measuring’, nor whether they would be appropriate for use with children. Insights are offered from the experience of the use of different types of SATs in various contexts, and the principles applied. It is demonstrated that no existing method effectively assesses the spirituality and spiritual care needs of children in hospital.

Chapter 5 reports on the qualitative research project undertaken to address the gap created by the absence of an age appropriate SAT suitable for use in a healthcare system. It outlines the ethical requirements, methodology; catalogues the items used in the SAT portfolio; and describes the processes and landmarks the refinements (called “Stages”) made to the proposed new SAT. This chapter also details the recruitment of 20 hospitalised school-age children from a large paediatric hospital in the UK as research subjects. It details how the use of play and storytelling was used to enable the children to engage with the SAT. The findings from these interviews relate to the design of the SAT portfolio, its linkages to the various stages of child development, the focus on the healthcare journey and the facilitating role of the assessor.

Chapter 6 summarises the data gathered during the research project, illustrating the breadth and depth of information collected. It documents the aspects of a child’s healthcare journey linking this to the need to devise an interpretative framework that provides a cohesive, comprehensive and clear description of what is being assessed.

Chapter 7 provides a thorough examination of the creation of an interpretative framework fit for use in a clinical setting. It explores the way in which conceptual constructs, such as “spirituality” and “religion”, have in the past been used to create meaning; suggesting that they play only a secondary role in describing the experience of children. In doing so, it is established that an appropriate conceptual framework should relate to the various stages of child development; be relevant to how children share information; describe the contextual dislocation of a child’s healthcare journey; and use language which effectively communicates with all disciplines in a healthcare setting.

The need for an appropriate conceptual framework leads to the introduction and development of the concept of “connectedness” which is key in facilitating the provision of a new professional language; and in shaping the theoretical basis for a tool which facilitates the sharing of information and meaning between the healthcare chaplain and the paediatric patient. This is backed up by the third aim which relates to the competences required by a professional to make the tool work. A theoretical basis is presented for choosing the concept of

connectedness. This provides a means to understand a child's sense of connectedness by identifying four dimensions; the momentum of connectedness, the resilience of connectedness, the awareness of connectedness and the evaluative nature of connectedness. A case study from the project is described to illustrate the information that can be accessed through this SAT.

Chapter 8 details the skills and competences required to use the SAT portfolio effectively in practice. These skills are defined as hospitality, liminality, reflexivity and fluency and are based on the concept of the Zone of Proximal Connectedness (ZPC) which combines Vygotski's concept of a Zone of Proximal Development (from his Social Cultural Theory) and Myer's application of Ritual Process Theory.

The final chapter offers a theology of connectedness as a reflective model of connectedness. It develops the rationale for a language of connectedness which considers the professional obligations in a healthcare setting; the identity of connectedness which establishes the professional parameters of disclosure; the encounter of connectedness which explains the significance of meaning between individuals; and the context of connectedness which argues for a wider application and explores the possibilities of reinterpreting faith-based concepts. In order to achieve this model, my thesis explores Bakhtin's dialogic principle.

This thesis tells the story of the research carried out in the pursuit of better spiritual care for children. This necessarily required an investigation of the definitions, meanings and usages of "spirituality". This led to the rejection of that term as it was not functionally appropriate for clear delivery of care and a more robust concept was identified, relating to spirituality, children, healthcare, communication and competences. Through the lens of child psychology, a Spiritual Assessment Tool (SAT) is developed and refined that enables engagement with children in a manner that suits their way of sharing information, through a set of child-centred tasks designed to be interactive and fun. Using the SAT, data are generated which provide insight into the perspective of the hospitalised child and therefore a new approach to children's spirituality and spiritual care<sup>3</sup>. Recommendations are made for the future use of the SAT by others in healthcare settings. To add depth to the reflective process, consideration is given to the theological implications of the project findings and the agenda it presents for future explorations.

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<sup>3</sup> This is expanded in Chapters 7 and 8

**Who is the intended readership and how does theology assist as the primary discipline to locate this thesis?**

If the claim that chaplains are practical theologians is valid, then to some extent they are already implicated in action research. (Cobb, 2008, p.7)

*A. Introduction*

In undertaking research on the spiritual needs of sick children, a significant factor was which disciplinary resources should inform the work and its disciplinary location as a piece of critical research. The background provided here demonstrates a selection of issues considered in deciding the locus for this thesis. Examples from nursing studies and medicine are explored in order to illustrate how disciplines other than theology now explore spirituality and religion (Graham, 2008, p.16). The emerging field of healthcare chaplaincy studies is also considered as being the field from which this research emerges; from within a chaplaincy context but additionally drawing insight from wider processes of theological reflection. Lastly, healthcare professionals and theologians are identified as the intended readership of this project; a significant factor in locating the identity of this thesis.

*B. The disciplinary location of this thesis*

Initially, the character of this thesis may be identified through comparison with other disciplinary perspectives and their focusses of concern. As stated research on spirituality is no longer confined to the theological sphere (Barnes et al. 2000;1 of 17) the thesis could have been produced primarily for healthcare professionals who are seeking to offer the fullest range of holistic care to patients. The language and methodology of the thesis would have then focussed on data that related to this “particular audience”, and how my theoretical and empirical explorations and findings might be applied to the development of clinical practice. Anderson and Steen (1995) and Kloosterhouse and Ames (2007) represent two examples of how the nursing profession addresses the presence of spirituality and religion. Regardless of the research method, whether case study (Anderson et al., 1995, p.17) or self-reporting survey (Kloosterhouse et al., 2007, p.64), the intent is that research informed practice should lead to good practice. Like my own thesis, Anderson’s and Kloosterhouse’s papers both use psychological theories to gain insight into understanding child development. The intention of

these studies is primarily to improve practice and raise awareness of how nurses should consider the spiritual and religious needs of a patient.

Research studies in Medicine could also be placed alongside those in nursing studies which collate insights from research in child development and seek to understand how the use of spiritual assessment tools can improve practice for doctors working with paediatric patients. For example, Barnes' et al. (2000) provides an example of a medical response to issues raised by spirituality and religion and interrogates how these affect the ways in which a doctor responds holistically to the needs of their patient. The exploration of this question is justified by arguing that taking this aspect of humanity into account results in positive health outcomes. On that basis, undertaking spiritual assessment of patients is recommended to doctors (Barnes et al., 2000, 6 of 17). While clarity is sought when defining spirituality, there is, however, no deconstruction of conceptual tools through theological dialogue.

Continuing in a medical frame, Anandarajah and Hight (2001) consider how to access and profile patient belief systems through the use of a spiritual assessment tool using HOPE questions<sup>4</sup> (see page 146, footnote). Raising similar issues to Barnes et al., they acknowledge the significance of spirituality and religion to the provision of effective medical care (Anandarajah et al., 2001, p.81). Issues of importance include belief in God on the part of either patient or professional, and the ways in which a SAT could assist patients in their journey towards wellbeing (Armbruster, Chibnall, Legett, 2003, e227). The overriding concern of this article is to improve the authors' own professional performance, and those of their colleagues, by incorporating this knowledge into practice (Anandarajah et al., 2001, p.87).

### C. *Chaplaincy Studies*

This thesis could have been located in the emerging field of chaplaincy studies, to which it is clearly related. I am committed to engaging with those in my own profession beginning the very important work of reflecting upon their spiritual role as members of healthcare teams. I wished to make my own contribution to the future direction of healthcare chaplaincy through undertaking action research in order to improve healthcare chaplaincy practice.

I recognise that a great deal more chaplain led research is required before established approaches and protocols can be agreed between us. Cobb comments on the "paucity of

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<sup>4</sup> This SAT is documented later in the thesis.

research published by chaplains to date, and their limited engagement with the research of other disciplines into relevant subjects such as prayer and beliefs” (Cobb, 2008, p.5). However, new research is now being undertaken by many chaplains as there is an increasing realization that our practice and assumptions need to be subject to the kind of scrutiny now taken for granted in other areas of healthcare. Until this thesis no research had been carried out into encounters between healthcare chaplains and sick children, or into attempts to identify the most helpful methods through which to offer children appropriate spiritual care in a healthcare setting. The data produced through interviewing children using a SAT thus contributes to work in chaplaincy studies. However, it also develops resources through which we may begin to theologically engage with the experience of children. My data began to draw me towards themes and concepts which had clear potential for correlation with key strands in my faith tradition (Graham et al., 2005, p.155) (see pages 294 and 330).

It is the theological concern of this thesis to move beyond a practical consideration of caring professional responses. Nursing, medical and chaplaincy studies all display an appreciation of how spirituality and religion can enable professionals to address the needs of a patient. However, this thesis is about more than service integration, additionally focusing on conceptual integration. It is my conviction that theology, when constructed in a dialogical manner in conversation with other disciplines, will not merely broaden a knowledge base for good practice in healthcare chaplaincy. It will also reconfigure conceptual frameworks and offer new insights into theological concerns. I am convinced that theology is a distinctive arena for the formation of new ideas that are radical enough to challenge existing beliefs as well as question the premises held by other disciplines. In doing so the use of theology enables those who engage in such a process to talk about God in public (Graham, 2008, p.11). As such, it was appropriate that my thesis be a work of theological reflection.

#### *D. The theological model of this thesis*

The theological model adopts a dialogue in correlational terms, as first expounded by Paul Tillich (1968, p.69) who sought to make links between theology and psychiatry: a process further developed by Hiltner and others who held to the premise that such processes, “represented partial prefigurations of a deeper theological truth” (Graham, Walton and Ward, 2005, p.156). A dialogue is a multi-dimensional process. The thesis draws on material from many sources in an effort to open dialogue with resources from my faith tradition. Newitt

refers to this process as “narrative expression through dialogue” (Newitt, 2011, p.32). Scharen and Vigin evocatively refer to the way theological forms a deep engagement in dialogue which brings the possibility that a new body of thought might emerge (Scharen et al., 2011, p.66).

While theological dialogue is more explicit at the end of the thesis than in the preceding chapters, this does not minimise its importance to the work as a whole. Rather it was necessary to go on a research journey before the material emerged which I could then ‘put to work’ in dialogue with theology. On commencing the thesis journey, I was unsure which theological sources would eventually become most important to my understanding (Graham et al., 2005, p.157; Swinton et al., 2006, p.v). It has been a fascinating process to see the theological conclusions emerge from my research with the children who participated in this study.

The process through which research data generates theological insight is explored by Scharen and Vigin (2011), who provide a theological justification for ethnographic methodology. They ask two crucial questions which have assisted me in my journey: “why use a research methodology in this thesis to make a theological statement?” and “how do I achieve this responsibly?” (Scharen et al., 2011, p.60). The former question underlies my reflections here and the latter is addressed more fully in the Ethical Section of this thesis.

#### *E. The Readership of this Thesis*

The above discussion illuminates the complexity of engaging theology with healthcare practice and required a broad engagement with many different resources in an attempt to raise the profile of spiritual care for children in a clinical context. As such, I hope that nurses and other healthcare professionals will find what I have written useful; and that my thesis will attract a multidisciplinary readership who seek to increase their understanding of child development and explore how the application of a SAT might improve paediatric healthcare practice. However, I also hope that my work will contribute to theological thinking and offer insights to other systems of belief which seek to place their practice within a theological framework.

My theological conclusions are tentative and provisional, but they are an invitation to others to enter into dialogue. Nurses and other healthcare professionals will, I hope, find valuable insight to inform their own disciplinary debates. However I also hope that they may be motivated by theological concerns and recognise that what is happening to sick children in a Glasgow hospital raises questions about what kind of God we believe in, and how we might understand ourselves as believing people. Scharen et al. underline the premise of this thesis when they say that:

Theology does not emerge from a vacuum; concrete dilemmas and encounters inspire its creation” (Scharen et al., 2011, p.66).

### *Summary*

This section has identified a strong trend in research in healthcare disciplines of engagement with topics related to spirituality, belief and religion. The motivation behind this trend is to deliver good practice that respects the spiritual and religious needs of patients. This thesis also provides pointers for good practice for a readership that includes medical practitioners and chaplains. However, the thesis offers more than a multidisciplinary approach to spiritual care. It aims for a more radical contribution; one that deconstructs some of the existing premises held by these other disciplines. I seek to make a theological contribution that offers not only a helpful narrative to justify spiritual care in a clinical setting, but that yields an emergent theology grounded in newly investigated dialogical encounters.

## **Chapter 1: Entering the realm of defining *spirituality* to adopt an interpretative framework to apply to this thesis: a literature review**

### **A. Introduction**

This chapter will focus on the development of a clear professional language to enable the articulation of the complexities of a child's spirituality in a healthcare setting. In doing so, it will explore the struggle to establish the meaning of the term "spiritual" with reference to the concept of "spirituality". It will provide an overview of current thinking and research on "spirituality" in the paediatric healthcare context, highlighting the key difficulties involved in relating spirituality to religion and considering how we understand children's spiritual needs. In doing so, it will necessarily assess the adequacy of previous definitions provided by those working in healthcare, examining how these definitions relate to paediatric patients, and discussing the possible intrinsic triggers for identifying spirituality in a child. Examining these areas will assist in reaching a definition of "spiritual" that is applicable to paediatric healthcare. It will also establish the need to develop, and put in place, a professionally accessible concept that provides an appropriate, interpretative framework to inform the design and use of an assessment tool to assist in the identification of paediatric patients' spiritual needs.

The re-definition of spirituality for the paediatric healthcare context enables the development of a Spiritual Assessment Tool (SAT) that provides the healthcare chaplain with an appropriate framework to communicate data gathered from assessment. The effective communication of such data may assist in caring for the spiritual needs of sick children in hospital. However, it is first necessary to be clear about the meaning of 'spirituality' in terms of how it relates to children and how it is formed in children. Existing literature provides definitions that are broad and contested, providing no basis for a shared professional language. Moreover, it is only recently that research on children's spirituality has started to emerge but little research has been carried out on the way in which spirituality is framed in a paediatric setting.

The question at the heart of this thesis arises from a desire to clarify my role as a healthcare chaplain employed by the National Health Service (NHS) in Scotland. The responsibility of a healthcare chaplain is encapsulated in a question that refers to the basic focus of the role; "what are the outcomes for a sick child's healthcare journey when visited by a healthcare chaplain?" Patients and parents often ask what the role of the chaplain is, and the answer

tends to focus on the offering of ‘care’ in a broadest sense. The NHS in Scotland describes this more specifically as ‘spiritual and religious care’ (NHS, 2002) and I have often described my role as being to support children and their spiritual needs. However despite how the NHS outlines my remit, or how I explain it to others, I still feel the need to measure how I offer support and care as a healthcare chaplain.

It is important to identify the divergent nature of the factors which led to my motivation, as a healthcare chaplain, to pursue this research project. The project is focused on a patient on a healthcare journey coming into contact with a chaplain. My motivation is to generate data, making use of a clear, conceptual language to more accurately describe and explain “childhood spirituality”. This entails testing existing terminology to assess its utility in effectively communicating my remit. Doing so necessarily raises questions about the nature and meaning of spirituality; if and to what extent it is different from religion; the extent to which existing terminology is appropriate for describing children’s spirituality; and the implications of the research findings in a healthcare context.

## **B. Background - An inherited dilemma contributes to the current professional struggle**

Healthcare chaplains struggle to apply government terminology and assumptions which provide little in the way of guidance on how to nurture appropriate practices to fulfil their remit. Given that government legislation requires NHS Boards to employ chaplains, this legislation directly impacts on practitioners’ roles and patient care.

In 2002, the Scottish Executive issued its 76th Health Department Letter (HDL), entitled *Spiritual Care in NHS Scotland* (Scottish Government, 2002). As an agenda for health, the HDL contained a document which detailed proposed changes to the structure and delivery of healthcare chaplaincy practice in Scotland, aimed at broadening the understanding of spiritual care for both staff and patients. In Yorkhill Hospital, like all other hospitals in Scotland, a legislative requirement was the development of a local Spiritual Care Policy and Action Plan (2003). In 2003, I was Head of Chaplaincy Services at Yorkhill Division, in what was then part of the Greater Glasgow Health Board (GGHB) and served on the Yorkhill Spiritual Care Committee that was responsible for the implementation of policy requirements. The newly formed NHS Greater Glasgow and Clyde Spiritual Care Committee’s policy that stated that “we are committed to providing holistic health care that is responsive to the physical,

psychological, emotional and spiritual needs of our patients” (NHS Greater Glasgow and Clyde, 2008, p.1). The challenge facing Yorkhill at that time was the management and operation of the policy in a paediatric context. This was acknowledged in the Yorkhill Spiritual Care Policy, which stated the need for a clearer understanding of the spiritual care needs of paediatric patients and their families (Yorkhill NHS Trust, 2003, p.1).

Since then there have been several developments; the most significant being in the form of the Chief Executive’s Letter (CEL) 49 (2008). Based on the Spiritual Care Revised Guidelines, which were produced by a Working Group established by the Spiritual Care Development Committee<sup>5</sup>, the CEL provides definitions of spirituality in terms of delivery of service. However, notably these definitions have remained unchanged since 2002. Under the section entitled Spiritual and Religious Care, the CEL states that:

5. It is widely recognised that the spiritual is a natural dimension of what it means to be human, which includes the awareness of self, of relationships with others and with creation.

6. The NHS in Scotland recognises that the health care challenges faced by the people it cares for may raise their need for spiritual or religious care and is committed to addressing these needs.

**Spiritual care** is usually given in a one to one relationship, is completely person-centred and makes no assumptions about personal conviction or life orientation.

**Religious care** is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community.

Spiritual care is not necessarily religious. Religious care should always be spiritual.

Spiritual care might be said to be the umbrella term of which religious care is a part. It is the intention of religious care to meet spiritual need.

(Scottish Government, 2009, Annexe A , p.1)

These statements offer broad definitions that are open to interpretation. There is no direct definition offered for religion or spirituality, only a description of spiritual and religious care. Using these definitions, Yorkhill Spiritual Care Committee was unable to define the exact

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<sup>5</sup> More background to the development of this committee is documented by Mowat and Ryan (2002, p.59)

spiritual needs of children, illustrating the limitations of this policy development<sup>6</sup>. The policy wording is problematic in a number of ways. The word “awareness” is used, with no definition, explanation or illustration of what is meant by it. The document indicates that this awareness might relate to “self”, “others” and “creation”, but with no explanation of how these qualities are, or might be, understood as being “spiritual”. There is no explicit indication of the nature of the significant connection related to these qualities. The term “spiritual” used in such a broad way, may camouflage detail of how such a construct is built and, as a result, ill-founded assumptions might be made. The lack of definition of the term “spiritual” points to the difficulty which arises from the use of such a potentially ambiguous term; and when there is insufficient clarity of definition, and depth of meaning, to translate the policy into professional practice<sup>7</sup>. The policy wording highlights that the tension between religion and spirituality remains when they are used as the dominant terms (Harrison, 1993, p.213). When these definitional perspectives appear in a government policy document there is an impact on the position of healthcare chaplaincy and how it is perceived by others. It is difficult too, to determine what is meant by religion and spirituality if a clear definition is not provided. Nothing in the statements contained in the CEL identifies how this policy might apply to a child’s understanding of ‘spirituality’ or ‘religion, or how spiritual care might apply to children in a paediatric setting. As such, the policy wording confirms the need for alternative terminology to facilitate better spiritual care for paediatric patients.

Ambiguity surrounding the definition of “spirituality” is not new or uncommon. In the United Nations Convention on the Rights of the Child 1989 (Seden, 1998, p.57, 59; Scott, 2003, p.117), the term “spiritual” is applied to media (Article 17), disability (Article 23) and development (Article 27). Article 32 states that:

1. Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be

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<sup>6</sup> This is a positive acknowledgment and indicates a willingness to explore, learn and adapt spiritual care accordingly. However, institutions can be organised that result in the delivery and development of spiritual care being marginalised, (Graber and Johnson, 2001, p.47)

<sup>7</sup> While some would argue that this is not the purpose of the policy, the professional bodies who produce competences and standards reflected nothing different from the government policy. (Levison, Bullock, 2006, p.33) However, even this is a significant step forward when Vandecreek’s work on patient satisfaction revealed discrepancy between institutions in terms of their systemic accountability and the departments performance (2004, p.342) Fitchett, Meyer and Burton suggest that this can be optimised for patients who are elderly and have long hospitalisation (2000, p.185)

harmful to the child's health or physical, mental, spiritual<sup>8</sup>, moral or social development” (United Nations, 1989)<sup>9</sup>.

Whilst article 32 underlines the rights of children and specifically includes reference to supporting and nurturing spirituality, further definition is required for effective implementation (Seden, 1998, p.57, 59; Scott, 2003, p.117; Burycka, 2001, p.119).

Responsibility lies with governments to consider their legal position in relation to the mandate to provide for the spiritual dimension of children<sup>10</sup>. However, no consideration is given in policy to complications relating to children’s changing needs at different stages of development; and no specific guidance is given as to how that should be effected.

The response of children’s hospitals, such as Yorkhill, to the UN Convention on the Rights of the Child and the Scottish government agenda to establish spiritual care, placed responsibility on healthcare chaplains to meet the spiritual needs of children in hospital. However, Scottish government policy was put in place in the absence of research or guidelines on how to meet children’s spiritual care needs. Not only do existing government policies define spirituality in a vague manner, but there is a presumption that spiritual needs are present even though no research has been carried out on the spiritual needs of paediatric patients in the UK. In addressing this absence, this research provides the basis for an appropriate conceptual framework for the spiritual assessment of children.

In 2001, I took up the post of NHS healthcare chaplain at Scotland’s largest children hospital, the Royal Hospital for Sick Children at Yorkhill in Glasgow<sup>11</sup>. At this time I was concerned

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<sup>8</sup> This global statement does not always translate to national legislation. Watson (2006) records her concerns about how the spiritual dimension is not referred to in the document Every Child Matters.

<sup>9</sup> Available from: <http://www2.ohchr.org/english/law/crc.htm>, Accessed 6/7/12 This hyperlink takes you to Article 32.

<sup>10</sup> The level of such legislation that sought the primary needs of the child came into play in two well documented cases one with Katie Wernecke in 2005 when the Child Protective Services of the State of Texas intervened when the parents were seeking alternative treatment instead of the state treatment to continue for her Hodgkin's Disease. She died later in 2007. ( CBS. News.com 16 June 2005) <http://www.cbsnews.com/stories/2005/06/16/health/main702362.shtml> as at 18/1/10

This was also the case for Tyrell Dueck who died of cancer. There was dispute over the direction and timing of treatment between the family and Saskatchewan Social Services in Canada. He died in 1999 (CBC News Saturday, July 3, 1999 Available from: <http://www.cbc.ca/canada/story/1999/07/02/dueck990702.html> Accessed 6/7/12

<sup>11</sup> The Royal Hospital for Sick Children has 266 inpatient beds, 12 day case beds, and handles approximately 90,000 out-patients, 15,000 in-patients, 7,300 day cases and 35,000 A and E attendances every year. The hospital provides care for newborn babies right up to children around 13 years of age. Available from: [http://www.nhsggc.org.uk/content/default.asp?page=s762andloc\\_id=24](http://www.nhsggc.org.uk/content/default.asp?page=s762andloc_id=24) Accessed 6/7/12

that no research had been conducted into childhood spirituality in a paediatric healthcare setting. This sharpened my resolve and my research began during my final year Masters Dissertation entitled, “The Current Thinking of Healthcare Practitioners in the Delivery of Spiritual Care within the Paediatric Context.” (2004)<sup>12</sup>. Literature reviewed revealed that staff were ill-equipped to identify and understand the spiritual needs of children. Another indicator for the need for research was that during the development of hospital policy, I observed that children in acute paediatric settings in the UK had never been asked about their spiritual needs and so I called for this to be addressed (Bull, 2004). I coordinated and published two articles; one identified and analysed research on, “The spiritual needs of hospitalized school-aged children with complex healthcare needs” (Bull & Gillies, 2007); and the other reported on an audit of the training needs of staff, entitled “Can you help us to help you?” (Bull, 2006). The first article identified that:

What came through the children’s stories was how they valued good supportive relationships. The benefit that these children felt from these relationships was a sense of comfort and strength that could make a difference. The children’s stories also revealed the need to have confidence in the hospital environment, its procedures and staff. Play was also an important aspect of their lives, to enable friendship, receive support and to help engage with the environment. Play appears to be a means of instinctive connection that enables them to experience a sense of security. In addition, the value that these children placed on their home environment and family routine was quite apparent. ... The views expressed by the children about their God in the story were mixed, but each child’s views were consistent within their story. This question drew out some of the children’s expectations of relationships, their environment, the provision while in hospital and discharge from hospital. (Bull and Gillies, 2007 p.38)

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<sup>12</sup> The coinciding of this study and the outworking of the HDL over these 2 years (2002-4) allowed me to crystallise in my own mind the issues that I was facing in the responsibilities given.

Although conducted using only a small sample<sup>13</sup> the research provided insight into how the children perceived, responded to and interpreted their hospital environment and provided the justification for further studies focused on understanding children's spirituality.

The second study focused on staff views of spiritual and religious care and their self-assessment of capacity and competency to offer such care<sup>14</sup>. It found that although staff had an understanding of what spiritual and religious care might mean, many felt that they had neither the skills nor the personal resources to deliver it (Bull, 2007, p.32; Oldnall, 1996, p.142; Martsof, and Mickley, 1998, p.300; Narayanasamy and Owens, 2001, p.451)<sup>15</sup>. In addition, many staff were found to be uncertain about the focus of the care provided by a healthcare chaplain. In my case, this may have been due to me previously being a Church of Scotland parish minister publicly associated with the Christian faith<sup>16</sup>; prompting ambiguity in the minds of respondents as to the focus and nature of the care provided. Mowat and Swinton (2007, p.18) suggest that employing healthcare chaplains from faith communities may contribute to confusion and uncertainty of what spiritual and religious care might consist of. In a previous training needs analysis study, it had become apparent that other staff members tended to perceive me as a religious faith leader, rather than a spiritual care giver employed by the NHS. The dual role of a chaplain in providing spiritual and religious care caused non-religious staff to feel doubtful as to what form of care was on offer (Bull, 2006)<sup>17</sup>. This suggests that understanding the remit of my role is not just a problem for me, but also for other hospital staff.

These findings, combined with the introduction of overly broad government policy, demonstrated that staff felt that they did not have the skills or resources to meet the spiritual needs of children, but that the spiritual needs of hospitalised children were present and

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<sup>13</sup> There were five children recruited. This was due to the availability of children who met the strict criteria. The information was gained while the children in hospital through an interactive story technique that focused on a child in similar circumstances as themselves.

<sup>14</sup> This analysis used the 76th Health Department Letter (HDL), entitled *Spiritual Care in NHS Scotland* as its reference point

<sup>15</sup> Sellers and Haag record the type of spiritual nursing interventions that took place a decade earlier in America (1998, p.344) Taylor and Mamier documents how spiritual need maybe present but a patient may not seek help from nursing. (2005, p.261)

<sup>16</sup> I am employed directly by the National Health Service so I am not employed by the Church of Scotland but still hold my office as a minister of the Church of Scotland.

<sup>17</sup> In a training needs analysis conducted at Yorkhill, there was opportunity for staff to respond in a free text box at the end of a tick box questionnaire. The majority of the comments made by 9% of the respondents made reference to the dual role of the healthcare chaplain to deliver both spiritual and religious care. They felt this confused and limited the delivery of care available. See also Lehair (2005), p.25 and Grosvenor, 2005, p.6

required attention. In an attempt to remedy this situation, this project will provide staff with a resource which clearly identifies and defines paediatric patients' spiritual needs and in doing so, I hope to resolve staff's lack of confidence in their skills to address children's spiritual needs. The resource developed will demonstrate how to identify and describe spiritual needs, and also identify the skills required to acquire and use that information.

Uncertainty about spiritual and religious identity within the community was highlighted by Peter Brierley's comments (in the Scottish Church Census of 2002) on the decreasing relevance of religion to children under the age of 15 in Scotland<sup>18</sup>. Although Christian religious observance is not absent from society (Bradley, 2007, p.33; Campbell, 2006, p.22; Culliford, 2002, p.1434), its former predominance has gone and religious rituals and doctrines no longer shape the mindset of the younger generation (Brierley 2003, pp.51-52; Hay, 2002); and others suggest that religion is insignificant (Paley 2007, p.179). The uncertainty amongst the older generation towards the perceived dual role of healthcare chaplains may be replaced by the different attitude of the younger generation who may view healthcare chaplains associated with faith communities as being irrelevant<sup>19</sup>. This highlights the possibility that the terms "religion" and "spirituality" could become redundant within a paediatric context, presenting a challenge to healthcare chaplains. Chaplains may be viewed as offering care which has little relevance for children who are unlikely to make any distinction between spirituality and religion. However, although there may be a low level of spiritual literacy amongst the younger generation in relation to the terminology associated with religion, the spiritual need, however it is defined, may still be high.

The challenge is further compounded by what Hay has called the "inarticulacy ... of an under-privileged education" (Hay, 1998, p.16). Although a contentious point of view, it may be relevant to the context of Yorkhill Hospital in Glasgow; a city which suffers from huge problems related to poverty and deprivation<sup>20</sup> (NHS Greater Glasgow and Clyde, 2008, p.4).

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<sup>18</sup> This article profiling America would also suggest a similar ambiguity (Marler and Hadaway, 2002, p.294)

<sup>19</sup> This maybe an inevitable outcome of a collective deconstruction but the result is a society that has lost a meta-narrative, a point made clearly by Hay (2000).

<sup>20</sup> BBC News article reports on this issue. Available from: <http://news.bbc.co.uk/1/hi/scotland/2804895.stm> (Accessed 9/7/12) "The statistics published by the Scottish Executive said that 16 council wards within the city featured in the 20 worst areas. Glasgow is also home to the three wards which come out worst on the list - Keppochill, Drumry and Parkhead."

A theological enquiry into these issues is exploited by Johnstone (2005). A psychiatric led study in America also focus on these social issues and assert that the integration of spirituality into the care of the patient would counter these problems, Mabe, P. A.; Josephson, M. A.; (2004. p.114)

A significant proportion of Yorkhill's patients come from deprived areas<sup>21</sup> and may find the distinctions between spirituality and religion incomprehensible. A new, more accessible approach to defining childhood spirituality and assessing children's spiritual needs would be a positive step to resolve these difficulties and provide a meaningful expression which could be applied to paediatric patients' perception of their surroundings. The onus is on those responsible for implementing public policy to meet and relate appropriately to the public need.

Government policy and global documents place a responsibility on healthcare chaplains to care for the spiritual needs of hospitalised children. However, at present, healthcare chaplains are provided with insufficient detail as to what spiritual care should mean in practice. Current terminology does not complement the cultural perceptions of staff who work alongside healthcare chaplains.<sup>22</sup> The struggle to deliver appropriate professional care raises questions such as; what is spirituality; what is the difference between religion and spirituality; how does this relate to children; and how is such spirituality formed within children? The next section provides an overview of approaches to resolving these important questions.

### **C. An overview of the factors contributing to this professional struggle**

#### *1. What is spirituality?*

Although spirituality is not defined or even mentioned in the Scottish government Chief Executive's Letter (CEL) 49 (2008), the word "spiritual" is used, but with no clear definition. Spirituality has emerged as an important word to describe a human phenomenon that is part of academic thinking, institutions and religions (Hay, 2006, p.xi). Currently the term "spiritual", according to Hay, functions as "a portmanteau word" (Hay, 1998b, p.5); what Smith et al. call "an umbrella term or catchall phrase" (Smith and McSherry, 2004, p.309). This usage of the term has spread through disciplines such as theology (Lynch, 2007), psychology (Fontana, 2003; Miller and Thoreson, 2003, p.33), anthropology (Tisdell, 2003) and sociology (Wexler, 2008), with each discipline viewing spirituality from its own distinct perspective. The term is also used in popular culture, appearing in life-coaching and self-help

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<sup>21</sup> For details of official statistics on levels of social and economic deprivation in Scotland see: <http://www.scotland.gov.uk/Topics/Statistics/Browse/Social-Welfare/TrendSIMD>

<sup>22</sup> At a later stage it will be evident that children have not been consulted in the process and are unlikely to own and use such terminology to describe their situation. No account has been taken of evidence which indicates that staff feel inadequate to take on this responsibility and that children do make expressions that correlate with, what has been called in the past, spiritual need.

books (Miner, Dowson and Devenish (eds.) 2012). The widespread use of the term has led to confusion as to its meaning but it is so pervasive in current parlance that it cannot be ignored (Cousins (ed.), 1980-1990)<sup>23</sup> or rejected (Draper and McSherry, 2002, p.1). Particular definitions of spirituality are used in a wide variety of areas such as current social policy and in the fields of health (Narayanasamy, 1999b), education (Hyde, 2007, p.98; Rossiter in De Souza, Durka, Engebretson, Jackson and McGrady (eds.), 2006, p.183) and social work (Hodge, 2005).

The increasing interest in the concept of spirituality includes interest in children's spirituality in the fields of psychiatry (Cole, 1992; King, Jones, Barnes, Low, Walker, Wilkinson, Mason, Sutherland, and Tookman, 2006, p.423; Josephson and Dell, 2004, p.8; Mohr, Gillieron, Borrás, Brandt and Huhuelet, 2007, p.251), psychology (Fowler, 1995), education (Meehan, 2002, p.292; Adam, Hyde, and Wooley, 2008; Hyde, 2006; De Souza et al., 2006) and children's spirituality in faith community settings (May, Posterski, Stonehouse and Cannell, 2005; Watts, Nye, Savage, 2005 ). For the caring professions, acknowledgement of a spiritual dimension makes it necessary to provide a clearer interpretation of what spirituality actually means in order to know how it relates to an individual (Chiu, Emblen, Van Hofwegen, Sawatsky and Meyerhoff, 2004, p.406; Emblem and Halstead, 1993, p.42).

## *2. The impact of religion on the defining of "spirituality"*

The context outlined above indicates that when exploring the meaning of spirituality, the role of religion should form part of that discussion. In constructing a definition of the concept that is more suitable for paediatric patients, it is necessary to first consider how the concept of spirituality relates to religion (Boyatzis, 2003, p.217).

The discussion on the relationship between spirituality and religion can be divided into three main viewpoints. The first is that spirituality and religion are the same (Hill and Pargament, 2003, p.64; Zinnbauer, Pargament and Scott, 1999; Bull, 2006). This can be seen in two different manifestations. Firstly, some individuals do not relate to or identify with either term; assuming spirituality and religion are interchangeable, they view themselves as being non-religious and therefore not spiritual. A second view, in some religious circles, might consider

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<sup>23</sup> This was an extensive series on world spirituality that also included secularism, edited by Peter H. Van Ness, entitled *Spirituality and the Secular Quest*

anyone outside of their faith community as not being spiritual, as they do not subscribe to the creedal statements of that particular faith community; they consider that true spirituality cannot be discovered outside of a particular religion (Hart and Schneider, 1997, p.264; Kuuppellomäki, 2002, p.209; Watson, 2000, p.99).

The second view is that spirituality and religion are completely different in substance. Spirituality is seen as a private and personal matter, which is organic, fluid and free in form, whilst religion is perceived to be more institutional, public, rigid and fixed. Stanard, an American counsellor, states that:

Spirituality includes concepts such as transcendence, self-actualisation, purpose and meaning, wholeness, balance, sacredness, altruism, universality, and a sense of higher power. Although these constructs are shared with religiosity, the latter is generally thought to encompass qualities of an organised institutional affiliation, whereas spirituality is described as being broader, more subjective yet universal experience (Stanard, Sandhu and Painter, 1998, p.209).

Roehlkepartain's (Roehlkepartain cited in Roehlkepartain, King, Wagener, and Benson (eds.), 2006, p.4) review indicates that those who hold the view that spirituality is separate from religion tend to portray other positions in a pejorative manner; unwittingly showing themselves to be elitists and implying that any other position is a degenerate, or, at best, poor, sibling of their own. As such, this position does not encourage dialogue or consider other views as acceptable, although it may highlight differences in how religion and spirituality are practised. It also suggests why difficulties and tensions arise; such concepts are imbued with the passion and commitment of those who embrace them and this can lead to division and conflict. If NHS policies relating to care use such terminology, less divisive alternatives should be considered.

The third view is where spirituality and religion are seen as being fundamentally different but with shared characteristics. Those who espouse this view may not consider there to be an equal overlap between the two. Some view religion as a specific expression of spirituality and would say that religion is encompassed within spirituality. This appears to be the predominant view shaping the definition of spirituality found in professional journals

(McManus, 2006, p.24). It is also apparent in the Training Needs Analysis conducted at Yorkhill, where “a significant proportion of staff (86%) identified that spiritual care and religious care are different but can sometimes overlap” (Bull, 2006, p.31).

While these viewpoints include a differentiation between religion and spirituality, applying them in a professional care setting has implications for how spirituality is understood, constituting a challenge to the development of a working definition (Mercer, 2006, p.501; Dyson, 1997, p.1184). In the past, spirituality was more clearly associated with religion, but many now feel comfortable talking about spirituality without committing themselves to any particular religion (Emblem, 1993, p.46; Dyson, Cobb, and Forman, 1997, p.1184).<sup>24</sup>

An important study of the impact of religion in defining spirituality was conducted by Smith and McSherry (lecturers in nursing). They addressed questions such as; “Is it possible to offer spiritual care to a person who is not religious without that person confusing it with religious care?” This problem of conceptual clarity has arisen as spirituality as “a term has been disassociated with its historical contexts and there seems to be an emerging form of spirituality that is individually determined and dislocated, resulting in a dilution of the term and, possibly, a loss of spiritual identity” (Smith and McSherry, 2004, p.310). Smith and McSherry see this interpretation as having a broader relevance to a secularized society; to be more “all-embracing and relevant to everyone, irrespective of religious tradition” (Smith and McSherry 2004, p.310). This interpretation reveals the confusion that can result from the dislocation of spirituality from religion. Professionals acknowledge the need to apply spirituality as a term in a secularized society where the less comprehensive term ‘religion’ was previously used (Lynch, 2007, p.24). However, unlike religion, which has clearly defined belief systems and practices, the idea of spirituality does not have a robust framework to allow for the assessment of patients’ needs.

One reason for the decline of religion is the emergence of other ways of thinking, such as humanism and spirituality (Emblem, 1993, p.46; Dyson et al., 1997, p.1185). This trend does not only affect religion. Spirituality has emerged as an alternative to scientific discourse which many consider to be inadequate to explain their perception of life (Henery, 2003,

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<sup>24</sup> Emblem (2004) also indicated that hospitals were a product of Christianity but with the secularisation of society these establishments have become independent from its roots. This is evident in Yorkhill, Royal Hospital for Sick Children who had, in the past, a picture of a Madonna and Child which has now been replaced.

p.552; Swinton and Mowat, 2006, p.42). Spirituality may provide a useful way to describe a person's view of the world. Religion, along with other belief systems such as humanism and atheism, appear as part of an old order where the focus on division would not be constructive for clinical practice. Spirituality forms a new perspective, drawing together many spheres of life once viewed separately and focuses more on commonality rather than division.

Pendleton, Cavalli, Pargament and Nasr define spirituality in such terms:

spirituality is a wellspring, an inner belief system or resource from which the child can draw strength and solace. Whether framed in terms of humanism, nature or religion, spirituality contributes to the child's ego-strength and resilience in coping with extraordinary stress (Pendleton, Cavalli, Pargament and Nasr, 2002, p.1 of 11).

This definition makes a distinction between spirituality and religion, where religion is viewed as one possible externalised expression of how a person's internal spirituality might be practised. This constitutes an elevation of spirituality above that of religion. However, despite this the question still remains as to the extent to which a new definition of this popularized term can overcome its association with religion; and the extent to which a sufficiently robust framework can be developed to describe individual spiritual perspectives in a way that others can understand. If patient care is to be clearly delineated and safe, it is necessary to replace spirituality with a new term *and* a new concept which is directly applicable to the healthcare context; to use a term and a concept which refers to the common characteristics of the different perspectives where the term might be used; Christian spirituality, atheistic spirituality, or new age spirituality.

The uncertainty in relation to the definition of terms is problematic in research also:

The ways in which the words [religiousness and spirituality] are conceptualized and used are often inconsistent in research literature. Despite the great volume of work that has been done, little consensus has been reached about what the terms actually mean (Zinnbauer, Pargament, Cole, Rye, Butter, Belavich, Hipp, Scott, and Kadar, 1997, p.549).

If confusion is so pervasive then it is arguably no longer appropriate to refer to spirituality in such a wide-ranging way. It is often used, for example, to replace other descriptive terms for healthcare models, such as “well-being”, “holistic”, “person centred” or “family centred” (Pfund, 2000, p.143). These terms describe a broad range of different aspects of care, whereas the term spiritual is often misunderstood as referring to only to one aspect of care. In trying to over-identify with the idea of spirituality, professionals are in danger of abandoning clear descriptions of different models of care within this context.

While some promote a comprehensive concept of spirituality (Pendleton, Cavalli, Pargament and Nasr, 2002), various disciplines compartmentalise it with the result that its scope of meaning becomes contracted (Pfund, 2000 p.143). Pehler, a nursing professional, states the categories of one such model, noting that “holistic care involves not only the physical and psycho-social needs, but also the spiritual needs” (Pehler, 1997, p.55). While Pehler extols the merits of holistic care and incorporates spirituality as a part of holistic care, the categorization results in a fragmentation of different aspects of a person. The result is a marginalization of the concept of spirituality as a ‘specialist task’ or the absorption and subsequent disappearance of the concept of spirituality into the philosophical framework of the discipline to which it is applied. Stanard, taking a more multi-dimensional approach, states that:

Human beings are not only psychosexual and psycho social, they are also psycho spiritual. As human beings are increasingly recognised as multi-systematic organisms, spirituality in human development is gaining legitimacy (Stanard et al., 1998, p.204).<sup>25</sup>

Compartmentalising such concepts, whilst perhaps a necessary analytical process for the professional, results in yet another possible way to redefine spirituality (Josephson, 2004, p.79). Pfund<sup>26</sup> addresses the issue of providing a definition relevant to care practice but expresses it in a more integrated manner by referring to Bradshaw, who states that “spiritual care is inseparable from physical, social and psychological care because it is indistinguishable from the wholeness of care” (Bradshaw cited in Pfund, 2000, p.147). This

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<sup>25</sup> This is underlined in the interviews conducted in the study by Hamilton and Jackson (1998), the research of Hill, and Pargament (2003) and case studies published by Prest and Robinson (2006, p.13)

<sup>26</sup> At the time of her publication she was a Royal College of Nursing Teacher at University of Nottingham

integrated model stresses the need to highlight the physical and spiritual interconnectedness of a human being (Kelly, 2005, p.15). The way that the concept of spirituality has been treated by professionals as existing alongside physical and psychological concepts demonstrates the need to be transparent about how it has been applied and interpreted. The approaches outlined here may be useful for care professionals within their own discipline but there is a danger that either the concept of spirituality is so broadly defined that certain assumptions are implicit, or so narrow that its priority is lessened in certain disciplines where so much else is demanded.

A new conceptualisation of spirituality is needed; one that is relevant in a care setting, useful for and meaningful to care professionals, and that taps into the realities current conceptualisations of spirituality and religion fail to describe. This new concept should more effectively relate to those who find meaning and purpose through different lifestyles which are not necessarily altruistic or aspiring to balance but which indicate a choice to connect with what provides meaning. A concept which espouses characteristics found in a certain type of spirituality may be elitist, exclusive and too rigid to address the range of diverse spiritual needs. Those who conceptualise spirituality in such a way may be accused of transferring values and agendas from their own spiritual world, creating what Anthony Bash (an Anglican minister who describes himself as an interested outsider to the healthcare discussion on spirituality) calls, 'a religionless religion' (Bash, 2003, p.12). In an attempt to break away from the fetters of religion they instead become another "religion". I propose that 'descriptors' be developed as the foundation of a framework that can observe the realities of patients' circumstances, in order to understand their spiritual needs and ensure that these needs are not interpreted in terms of pre-determined values.

In the light of these observations, it would be inappropriate for this research to adopt a value-based approach which identifies prescribed spiritual qualities. Nor will it use religion or spirituality as a primary means of describing spiritual need. These will be secondary concepts, present for those who describe their lives in these terms.

#### **D. Is this current overview adequate when relating to children?**

How does such a conceptual discussion about spirituality relate to children and how they understand the world around them? Smith and McSherry's study of the nursing profession, which focused on the care of children, highlighted the need to address the perception, definition and application of concepts of spirituality as they are applied to children:

It would seem that there is no real consistency in the way that the term is perceived, defined and applied to the practice of nursing. This is further compounded when applying the term to children because much of the language used and many of the perspectives adopted reflect an adult population (Smith et al. 2004, p.310).

In their view:

There is a paucity of research on children's conceptualization of spirituality, and the link between spiritual development and a child's socialization process (Smith et al. 2004, p.314).

In addition to moving away from defining spirituality in terms of its association with religion, there is a need to move to develop a concept of spirituality that is relevant to a child's perspective. This is not to exclude religion, or even spirituality, but to focus on what is most appropriate to children's perceptions of their view of life in the healthcare context. Research with children cannot be dominated by the historical journey of how the concept of spirituality and religion related to each other in the past; it must relate to children's present experience (Hill, 2006, p.72).

The direction and emphasis of past research has been concerned with the development of spirituality in terms of its relationship with religion. This was observed by Radcliff and Nye who concluded that the historical development of spirituality as a concept, in relation to Religious Development Research over the past century, had focused on Western Culture with a bias to Judeo-Christian beliefs and a heavy dependence on stage-orientated theory.

However, they note that this changed when Robert Cole<sup>27</sup> published “The Spiritual Life of Children” (1992), and introduced new concepts, such as “atheistic spirituality” which was similar to Fowler’s inclusive description of faith (Fowler and Dell in Roehlkepartain et al. (eds.), 2006, p.34). Radcliff and Nye propose that:

What followed Coles’ work was a shift in emphasis from religious development to children’s spirituality research, the latter often seen as separate from religion altogether. The shift was not as dramatic in the United Kingdom, where there was a greater familiarity with spirituality research by Alister Hardy<sup>28</sup> and Edward Robinson<sup>29</sup> (Roehlkepartain et al. (eds.), 2006, p.475).

Alister Hardy and Edward Robinson had laid the foundation for this conceptual shift in the European context, taking account of the cultural difference between Europe and America (Lynch, 2007, p.2; Kessen, 1979, p.819).<sup>30</sup> The American focus was on the religious development of a child and the benefits of that development to the child, whilst the European approach was more focussed on the intrinsic spiritual qualities of how a child perceived their surroundings irrespective of religion. Despite that cultural distinction, Barnes, Plotnikoff, Fox and Pendleton observe from Robert Cole’s extensive study<sup>31</sup> of children in an American context that “children in particular do not make sharp distinctions between spirituality and religion” (Barnes, Plotnikoff, Fox and Pendleton, 2000, p.889). If children make no such conceptual distinction, at what point does religious or spiritual meaning become distinctive for a child? There is increasing acknowledgement that when discussing conceptual understandings of spirituality there are new reference points which reflect the current

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<sup>27</sup> Robert Coles is a child psychiatrist who has spent his working life trying to understand the lives of children from a variety of backgrounds. The result of that effort has been a series of books that tell of the particular lives of boys and girls who live in different regions of the United States, and in foreign countries. Dr. Coles examined how children from a variety of backgrounds acquire religious values in various social and cultural settings and how these values connect with a given child’s life in *The Spiritual Life of Children*. Available from: <http://www.scottlondon.com/articles/coles.html> (Accessed 9/7/12)

<sup>28</sup> There is a biographical description by Hay (2006) about Alister Hardy in his book *Something There* pp.34 - 49

<sup>29</sup> Edward Robinson was the director of the Religious experience unit from 1976 – 1985 (Hay, 2006, footnote No.34)

<sup>30</sup> Paley would argue that very little comparison can be made between the cultures of the UK and the USA, (Paley, 2007, pp.176-178)

<sup>31</sup> Robert Cole in his book, “The Spiritual Life of children” has made an extensive study of children from a diversity of backgrounds. He is a child psychiatrist and a professor at Harvard University.

situation of children's lives, rather than merely referring to what is non-religious. This has been identified by professionals examining child development theories in psychology.

## **E. How is spirituality manifested in childhood?**

### *1. The spiritual life of children*

Discussion of spirituality in children has taken place through studies of children in everyday contexts where spirituality is assumed to be:

- learned by a child from experience (nurture)
- an innate mechanism which can be nurtured because it is already present in a person's natural disposition. (nature)
- a biological function identified by associating certain spiritual rituals with areas of activity in the brain (biological function) - see footnote under Section E.1 c).

#### *a. Spirituality as the nurturing of a child*

If spirituality is a learned experience, it may be assumed to be a culturally-based phenomenon that is localised in communities which practise forms and patterns of spirituality, meaning that it is not a universal quality but a specific expression within a certain community. In this view, religious communities can be viewed as being essential to nurture a spiritual lifestyle that meets a spiritual need. For example, the British Humanist Society contends that those who seek religious support in a healthcare setting should have this provided by their own religious community and not by the state<sup>32</sup>.

#### *b. Spirituality as the natural disposition of the child*

If spirituality is a natural disposition, and a universal feature of humanity, then with the provision of nurture, the potential is there for a person to grow up to be spiritually aware (Hay, 2006, p.33). Hay, Reich and Utsch state that:

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<sup>32</sup> Article in the Free thinker <http://freethinker.co.uk/features/spiritual-care-on-the-nhs-chaplains-or-charlatans/> as cited on 29<sup>th</sup> March 2010  
<http://www.ekklesia.co.uk/node/9181> as cited on 29<sup>th</sup> March 2010

Spirituality is an inbuilt feature of the human species that develops from the beginning of an individual's life ... our central contention [is] that spiritual awareness is biologically inbuilt in the human species (Hay et al. in Roehlkepartain et al. (eds.), 2006, p.47).

If spirituality is a universal quality then public institutions must ensure, as part of their care policy, that a spiritual dimension is supported and nurtured. For example, if a child is admitted to a hospital where the dominant culture differs from that of the child's home, this could have a positive (or negative) impact on the child during the healthcare journey (Silber and Reilly, 1985, p.223; Crisp, Ungerer and Goodnow, 1996, p.69; Rushforth, 1999, p.688; Carter, 2002, p.28; Pao, Ballard, and Rosenstein, 2007, p.2753). Studies have revealed that a low level of nurture for what may be a natural disposition can disguise or even devastate the spiritual dimension (Adam, 2008, p.33). It may be difficult to differentiate between what has emerged from natural disposition and what has been created culturally and if the nurturing of a child's spirituality is affected by the cultural environment, it is an important part of patient care to identify the spiritual needs of the child in hospital (Narayanasamy, 1999a, pp.279-280).

*c. Spirituality as the biological function of the child*

Newberg, D'Aquili, and Rause (2001)<sup>33</sup> sought to prove that certain spiritual activities are associated with certain activity in the brain. This approach built on the work of British zoologist Alister Hardy (1966)<sup>34</sup> who argued that spirituality was part of the process of natural selection. Hardy's work has been supported by studies that attribute spirituality to a specific domain in the brain which could be developed and used to "facilitate the process of adaptation to an environment" (Adams et al., 2008, p.16). Adams, an educationalist specialising in children's spirituality, asserts that neuro-physiological studies indicate that "from a biological perspective, parts of the human brain may have evolved which effectively render all human beings capable of being spiritual" (Adams et al., 2008, p.17; Hyde, 2004b, p.44). This is based on Newberg's research on "functional neuroimaging"<sup>35</sup> which focuses on religious and spiritual phenomena. These studies have combined the "phenomenological

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<sup>33</sup> <http://www.andrewnewberg.com/default.asp> as cited on 29th March 2010

<sup>34</sup> This was published in the *Divine Flame*

<sup>35</sup> "Functional neuroimaging is the use of neuroimaging technology to measure an aspect of brain function, often with a view to understanding the relationship between activity in certain brain areas and specific mental functions. Cited in the *Science Daily* – the website source for latest research news 10.9.12

aspects of spiritual development with observed changes in brain function over the life span of the human being” (Newberg and Newberg in Roehlkepartain et al. (eds.), 2006, p.193). Further insight into how the brain functions may enable healthcare professionals to ascertain a child’s capacity to adapt to a changing, and perhaps challenging, environment (Thurston and Ryan, 1996, p.14; Tu, 2006, p.1030). If spirituality were found to be a universal phenomenon, this would explain much of human culture, ritual, belief, health, identity and behaviour (Roehlkepartain et al. (eds.), 2006, pp.9, 19; Fina, 1995 p.557; Thorenson, 1999, p.298; Seeman, Dublin and Seeman, 2003, p.53). However, the biological function approach merely locates the physical existence of spirituality; it does not establish the characteristics of what spirituality might look like in children at any given point in their development. If more scientific evidence is produced, it may allow for more credence to be given to the idea of the universal significance of spirituality.

## *2. Studies in the spiritual life of children*

In order to provide a basis for discussion, two studies will be examined which draw from these perspectives of the spiritual life of children.

### *a. A Study of children in an educational setting*

A landmark study by Hay and Nye, published in *The Spirit of the Child* (1998), aimed to differentiate between universal identifications of spirituality and those specific to children (Hay and Nye, 1996, p.8). Although the cultural practices of a child might change, according to Hay, spiritual awareness would remain as a resource present within the child<sup>36</sup>. The main theme emerging from this study was the term “relational consciousness.” This theme was subsequently developed further, and Hay states that “Spiritual talk . . . was identifiable because it always had to do with relationship, not only relationship to God, but also relationship to other people, to the environment and even to oneself” (Hay, 2003, p.4, 121).

Hay and Nye observed that:

There is a form of awareness, different from and transcending everyday awareness, which is potentially present in all human beings . . . The many religions of homo sapiens are the richly

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<sup>36</sup> This framework was built on 38 interviews conducted in England with children from different religious, non-religious and ethnic backgrounds.

varied cultural responses of human beings to their natural spiritual awareness (Hay and Nye, 1998, p.10).

Hay and Nye describe “spiritual awareness” as a process whereby a child becomes aware of the diversity of available connections that can bring value and meaning to existence (Nye and Hay, 1996, p.147). Carter called this the “rudimentary core” of a child’s spirituality (Carter, 2007, p.57). Hay and Nye’s study does not use scientifically measurable evidence as Newberg’s does, instead recording children’s well articulated accounts of intimate transcendental experiences. The children’s willingness to share these experiences is significant in its contrast with a study conducted by Adams, who recorded adults sharing childhood experiences which they had previously suppressed due to embarrassment (Adam et al., 2008, p.33; Farmer, 1992, p.267). At the core of a child’s spirituality there are certain common components which Hay and Nye refer to as “awareness sensing”, “mystery sensing” and “value sensing”. The concept of childhood spirituality, entitled relational consciousness, served to reflect the central importance of relationships in children’s understanding of their own spirituality.

*b. A study of children in a nursery setting*

Champagne’s study of Canadian pre-school children explains children’s spirituality in different terms, focusing on children’s behaviour rather than their articulation, and involved observing sixty children, aged between 3 and 6 years, for 100 hours of “daily life situations”<sup>37</sup> (Champagne, 2003, p.44). Focusing on how the children presented themselves in sensitive, relational and existential modes of being Champagne refers to the children as ‘spiritual beings’, noting that “looking for children’s spirituality then calls for an awareness of the children’s mode of being” (Champagne, 2003, p.44). Referring to children’s spirituality as “being-in-the-world”, the mode of *being* is used as a means to interpret and understand how the children present themselves through their behaviour; the manner in which they behave towards one another being assumed to demonstrate their manner of living. Observing behaviour patterns in a social setting provided insight into the children’s perspectives on their world. The study suggests that at a very early stage in a child’s development, there are indications that a child’s “sense of being” is expressed through social behaviour. However, it is difficult to ascertain the extent to which this mode of being is

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<sup>37</sup> These daily situations took place in a child day care centre.

learned from other children or is an intrinsic natural quality. While Champagne describes a phenomenon that could be considered to be social behaviour, she is trying to explore early signs of spirituality; to deduce this from children's behaviour and interaction and to relate her findings to a wider discussion of spirituality.

### *3. Discussion of Section E*

Hay and Nye and Champagne's studies provide a strong indication that biological make-up and cultural nurture provide evidence of what is referred to as spirituality; and that it is part of a person's intrinsic and cultural identity. Champagne demonstrates that spirituality is observable through behaviour and Hay and Nye's study suggests a generic structure for spirituality that is more than culturally constructed. Hay proposes that 'spiritual awareness' takes an unspoilt form within children before they are influenced by a secular culture which suppresses these qualities<sup>38</sup>. What both studies describe as spirituality is present but in a different form than that found in adults. Hay et al. highlight the difficulties of exploring children's spirituality:

We suggest that the natural spiritual awareness common to all human beings has, during the course of human history, become overlaid by a socially constructed secularist critique that denies its reality..... one corollary of this conjecture is the expectation that the most likely place to find openly admitted spiritual awareness is in young children, since they have not yet assimilated the cultural critiques of such awareness (Roehlkepartain et al. (eds.), p.53).

This appears to be a pessimistic view of the influence of cultural context on a child's spiritual awareness. The biological evidence identifying spirituality with a specific brain function continues to be contested. However, observational studies show that the concept of spirituality can be used to understand children and their perception of the world and characteristics of childhood spirituality such as "relational consciousness" and "a mode of being" have been identified. If these terms were to be adopted more widely, how would they apply to children in a healthcare context? Would these concepts, developed in school and nursery settings, be sufficiently to describe children's hospital experience?

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<sup>38</sup> Kemper and Barnes acknowledge the suppressing nature of America even on other sub-cultures contained within the United States, (2003, p.205)

Applied together, nurture, natural disposition and biological evidence offer a general basis for understanding a child's spirituality. For example, if a child has a routine of saying bedtime prayers with a parent, there are three possible aspects of spirituality which may be taking place. The child's prayer may relate to a natural human disposition such as the expression of fear but it may also relate to something which has been taught by a parent and is therefore the product of nurture. The time spent praying might be appreciated by the child because it is quality time with the parent. Discussion between child and parent could increase the child's capacity to use that as a coping strategy at other times. A neurophysiologist might monitor the type of brain activity occurring during this bedtime prayer, and find brain patterns associated with this routine time slot that correspond to the mood of the child at that time. Although this discussion of the concept of spirituality does not explain how it develops, or how spirituality might be assessed in children in hospital, it provides a basis and justification for further enquiry.

We must be clear about what is being described by 'spirituality' and how it relates to a child, taking into account both natural and cultural factors in child development and their impact on spirituality.<sup>39</sup> Children in hospital, who may have rejected their normal cultural practices, may not have lost their natural spirituality although they may need support to meet spiritual needs which are no longer being addressed in the hospital environment. Observational studies claim to detect signs of spirituality in children and investigations into the behavioural, cognitive and biological make-up of children support this. It would appear that without appropriate nurture, spirituality does not flourish. It is asserted that spirituality is a natural human disposition and can be observed in children through what has been called "relational consciousness" and "spiritual modes of being." While the presence of spirituality in children is not in doubt, further consideration is required to understand its function if professionals are to offer informed, appropriate care.

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<sup>39</sup> In the current psychological field it is commonly accepted that there is interaction between nature and nurture as both contributing to the development of the child (Santrock, 1988, p.16).

## **F. Discovering a new approach to understand children's spirituality in a healthcare setting**

The aim of this project is to understand and provide an effective method of description of the spirituality of children in the healthcare setting, and will therefore study children at various ages and stages of development in a hospital setting. Existing studies stress that research needs to be observational and participatory and that it is vital that children should be involved in the research process. The involvement of children will be a significant and distinctive feature of my research project and children will be actively involved in the process of the study. This tends not to be the case in other studies which aim to inform those involved in spiritual care in a healthcare profession.<sup>40</sup>

The studies analysed in this chapter were identified through a literature search which focused on peer-reviewed journals and books on theology, psychology, sociology, education and art. The majority of studies were carried out in western, English-speaking, developed countries such as Canada, the USA, Australia and the UK, with some European and Israeli articles submitted to English-speaking journals. This suggests that spirituality is more widely discussed in the English-speaking world, with the possible exception of Spanish and Chinese speaking areas. Professional journal articles were drawn from the fields of nursing, education, medicine, sociology, psychology, and theology, in addition to specialist multidisciplinary articles focusing on spirituality and healthcare chaplaincy. These articles focus on investigating the current thinking of professionals associated with healthcare and working with children who are in hospital and exploring how a new understanding of spirituality might affect the way they carry out their duties.<sup>41</sup> The literature confirmed the existence of concern about children's spirituality amongst professionals involved in child healthcare. However, very few projects focused on the functional nature of children's spirituality in a healthcare setting. The review found no published research project where children in an acute

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<sup>40</sup> What I consider to be "an appropriate understanding" was to discover through children sharing about their lives in a setting and method that was conducive to sharing.

<sup>41</sup> The key words used in the literature search have included, paediatric, pediatric, children, child, childhood, healthcare, hospital, spiritual, spirit, spirituality, religion and assessment. These words were used in combination with each other to assist in focusing the search.

paediatric context contributed directly to the evidence gathering process through direct communication with the researcher.

Studies related to spirituality in a paediatric setting do exist but their methodology tends to focus on children reporting to the researcher through other adults. A study conducted by Feudtner, Haney and Dimmers explored children's spiritual needs from the perspective of American Pastoral Care providers (Feudtner, Haney and Dimmer 2003). Despite being an American study, where a strong theistic spirituality often permeates<sup>42</sup>terminology (Anderson and Steen, 1995, p.15; Handzo, 1990, p.18), the study offered a broader definition of spirituality including religion as a constituent component which may be relevant to the conceptual structure currently used by the Scottish government. However, the methodology focused only on the perceived needs of the child with nothing being considered from the perspective of the child. Feudtner admits this and recommends that children should be directly involved in order to obtain their perspective (Feudtner et al., 2003, p.71).<sup>43</sup> This acknowledges that children can and should contribute to the knowledge base required to better understand childhood spirituality in a healthcare context. New perspectives and insights are possible if children are given the opportunity to describe their needs and experience of care, and if the information received is compared to that of the professional adult perspective in the same setting. Direct comments from children would provide data which aids understanding of the spiritual needs of children are in hospital and of the reasons why these needs emerge.

A small number of articles that focus on health and school-age children involve researchers engaging directly with children: Pendleton et al.<sup>44</sup>, Ebmeier, Lough, Huth, and Autio and Wilson (Pendleton et al., 2002; Ebmeier, Lough, Huth, and Autio, 1991; Wilson, 1994)<sup>45</sup>. These studies used interactive techniques which enabled children to contribute directly to the research project. However, the projects reflect American religious culture (Lynch, 2007, p.2), and accord prominence to a religious framework which defines spirituality in theistic terms.

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<sup>42</sup> Harris, Thorensen, McCullough, Larson, (1999) use a more scientific narrative without the religious overtones of other articles but still have a direct religious care agenda.

<sup>43</sup> This is a similar limitation in another study exploring the spiritual development of sick children, Pridmore and Pridmore, 2004, p.25)

<sup>44</sup> This American study interviewed 23 cystic fibrosis patients aged between 5 to 12 years old and their parents. The children were interviewed and asked to draw themselves and God and asked to explain the significance of the drawing.

<sup>45</sup> Thomas and O'Kane are a good example from the field of social work (2000).

Ebmeier's data was gathered from an American Catholic Hospital in the Mid-West, and focused on the children's views about God in relation to their health. Pendleton et al. (2002) show a clear theistic emphasis which shaped their approach to study of the religious and spiritual coping mechanisms of children with cystic fibrosis. Whilst these studies engaged directly with children, the terms of reference for defining spirituality and the conceptual constructs developed reflected the American context. As such, they do not relate to the European cultural setting or the non-theistic definitions developed in this project (Lynch, 2007, p.3; Pargament, 1999, p.36; Stifoss-Hanssen, 1999, p.26; Benson, 2004, p.49).

As the data in my study was gathered in Scotland, it is appropriate to root the discussion on the definition of spirituality in the European culture. European research into childhood spirituality appears in the fields of educational and developmental psychology and in the work of educationalists (de Souza et al. (ed.), 2009) in response to Hay and Nye's book on childhood spirituality published in 1998. Hay and Nye were the first to research childhood spirituality with children in an educational setting, using a non-theistic, definitional framework. Although their study had similarities with my project (in engaging with children and the nature of conceptual constructs), it is important to note that the educational context differs from the healthcare context, as the healthy children in Hay and Nye's study cannot be assumed to have had the same spiritual needs as sick children in hospital. When spirituality is discussed amongst professionals in a healthcare setting, the predominant concern is the well-being of the patient. Although Hay and Nye's research was carried out in the UK, the educational context differs sufficiently from the healthcare context for its results to be of limited application to this study.

However, these studies provide reference points for my research project in evolving an appropriate non-theistic conceptual construct to operationalise a child's spirituality in a healthcare setting. Kenny (1999a), a UK nurse, states that "the challenge to paediatric nurses is to seek a clarification of spirituality that is both applicable to children and underpinned by a strong theoretical definition. Only when this is in place can there be an effective change in clinical practice" (Kenny, 1999a, p.31). I suggest that for this to be achieved it is necessary to interview children while they are in hospital.

### *Summary of Section F*

Reviewing existing research on spirituality and developing from my own publication in 2007 (Bull and Gillies, 2007), the most appropriate approach for this project is to interview children in a healthcare setting using a conceptual construct which takes account of how the children manifest their spirituality.<sup>46</sup> In doing so, this project will be the first to provide professionals with a working definition and tool which they can use to identify and assess children's perceived spiritual needs. In order to achieve this I will explore children's understanding of their own spirituality and investigate how it can be understood by healthcare professionals in an acute paediatric setting.

It is vital to adopt an approach that is inclusive and genuinely child-centred. As healthcare chaplains operate in a secular context, they must disentangle themselves from inherited terminology which does not explain the nature of spirituality in hospitalised children. Formulating a new conceptual construct to describe this would provide an approach that enables direct engagement with children and provides the insight to effectively assess the spiritual care needs of hospitalised children.

### **G. Developing a concept to operationalise spirituality**

To develop a new and appropriate conceptual construct, the concepts of religion and spirituality must be superseded by an interpretative framework to explain spirituality not in general substantive terms, but in contextual and functional terms, so that spiritual needs are identified and understood through the way children present them.<sup>47</sup> This project will offer an interpretative framework that constructs and communicates its meaning from conversation and construct a new conceptual understanding of spirituality by how it is presented through

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<sup>46</sup> This form of research allows for a more descriptive insight. This has proven to be successful in other areas of healthcare research, (Borreani, Miccinesi, Brunelli and Lina 2004, p 2 of 9.

<sup>47</sup> This may be viewed as a reductionist view of spirituality but rather Paley illustrates that this process is valid in understanding how a phenomenon might work, (2010, p.187).

“Thus, if one aspect of functional spirituality is the human search for meaning then carers will need to develop approaches and methods to enable them to deal with the existential quests of people in times of illness (Breitbart & Heller, 2003). If spirituality denotes a quest for hope, the desire for relationships, or the construction of purpose, then, again, various approaches and techniques will be required to enable nurses to care well for this aspect of people's lived experience of illness (Lopez et al., 2000). If spirituality is a search for God and the transcendent, then facilitating that quest requires a particular set of skills and knowledge of religious traditions, theology, religious practises, or at least an ability to recognize the need and refer to appropriate persons (Koenig, 1998)”. (Swinton, Pattison, 2010, p.227)

conversations with children. Its primary concern will be the “practical utility” of delivering care and ensuring that childhood spirituality is correctly understood.

Swinton and Pattison acknowledge the ambiguity and vagueness of the term spirituality, but consider this feature as a strength (Swinton, Pattison, 2010, p.227).<sup>48</sup> Their argument differs from the one made for an interpretative framework in this thesis. My intention is to offer the necessary clarity to make decisions for delivering care to children who are still formulating their sense of meaning of the world. Despite our differences there is some agreement between this thesis and Swinton and Pattison’s article. The common ground lies in their understanding of the functional and situated nature of language. They state that:

A thin description of spirituality assumes it to be a mode of contextual language with practical intent, used in this case, as a means of highlighting and expressing deficits and absences within healthcare provision and initiating positive change (Swinton and Pattison, 2010, pp.232-233).

The interpretative framework to be employed in this thesis also has a functional nature that takes into consideration the social-political narratives of children. However, this thesis also argues that to sustain the rights of children, consideration must be given to their development and the contextual disruption experienced when being admitted to hospital.

If an interpretative framework helps a healthcare professional to respond responsibly to any narrative used by a patient, then this helpful distinction in the purpose of language allows both the patient to own their cultural language and professionals to facilitate a clear direction of care when the function of a patient’s narrative is understood. Much of Swinton and Pattison’s discussion about spirituality is in relation to adults’ understanding. While a language of spirituality may not be expressed by children, the phenomenon that it describes may still be present. In order not to overlay such an adult orientated language an

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<sup>48</sup> Thus, if one aspect of functional spirituality is the human search for meaning then carers will need to develop approaches and methods to enable them to deal with the existential quests of people in times of illness (Breitbart & Heller, 2003). If spirituality denotes a quest for hope, the desire for relationships, or the construction of purpose, then, again, various approaches and techniques will be required to enable nurses to care well for this aspect of people’s lived experience of illness (Lopez et al., 2000). If spirituality is a search for God and the transcendent, then facilitating that quest requires a particular set of skills and knowledge of religious traditions, theology, religious practises, or at least an ability to recognize the need and refer to appropriate persons (Koenig, 1998)”. (Swinton, Pattison, 2010, p.227)

observational interpretative framework can help a professional translate this in an accountable manner.

Therefore, what Swinton and Pattison have not addressed sufficiently is that there is not just a difference between what language is used for and how it works but that these two aspects can be separated. The patient, if they so wish, may speak in terms of spirituality or any other liberative or resistant narrative and the professional may even engage with the patient in such terms but the introduction of an interpretative framework allows the functional and situatedness of such language to be identified between professions. This is not to deny the fluid nature of such a concept as spirituality but to acknowledge that even fluids abide by certain laws of physics.

The separation of the functional nature of a phenomenon from the terminology of spirituality will be a feature of the interpretative framework and will be developed by devising an approach that avoid dichotomous polarised understandings; having as its focus the description of a patient's experience rather than using potentially conflicting conceptual terms such as religion and spirituality (Chiu et al., 2004, p.411). There is a need to select one theme that allows me to describe and relate to other definitional strands of spirituality in a more deliberate and explicit manner<sup>49</sup>. This would be difficult with some of the above concepts of religion and spirituality which would not constitute an inclusive approach (Chiu et al., 2004, p.409). The concept selected must be inclusive immediate descriptors capable of being applied to children that account for their situation as they perceive it based on their developmental stage; and enabling healthcare professionals to better understand paediatric patients in a healthcare setting.

Contextualising concepts such as religion and spirituality, through the use of a more appropriate concept, should overcome the polarity between understandings of religion and spirituality and instead centre the discussion on what is appropriate in describing children's needs. This shifts the focus from identifying a child's religion, if any, to identifying the ways in which they might use that religion in their current context. The concern is not to discover

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<sup>49</sup> In the case of describing another definitional strand of spirituality, such as spiritual experience in relation to connectedness, then the main focus is not on the nature of that spiritual experience, nor even its validity, but on noting that this is a point of connection in a person's life and exploring why that person wishes to make such a connection and what meaning is drawn from this experience as well how that connection is affected by the healthcare context.

the innate qualities of children's spirituality but rather to discover how the qualities of spirituality function in a given context. This is the information healthcare chaplains, and other professionals, require to access in order to deliver appropriate care. A new framework must take this dimension of hospitalized children seriously by providing a child and family-centred approach which allows concepts of spirituality and religion to be shaped by them, rather than them being slotted into an exclusive pre-existing conceptual category. This would constitute a move away from the categories currently used by NHS chaplaincy in Scotland.

Evolving an accessible and inclusive concept which can be shared between the various professions in paediatric care would address Tony Walter's concerns for the authenticity of this theoretical inclusiveness of an emerging spirituality. He states that "in theory the spiritual can include the religion, but in practice ... it may be used to exclude religion and religious personnel" (Walter, 1997, p.29). The adoption of a single inclusive concept removes the possibility of subversive exclusion of one professional by another, and addresses any subconscious or inadvertent bias. The inclusion of a new operative concept would have implications for the policy of the Scottish government which aims to equip professionals to offer spiritual care in a paediatric setting.<sup>50</sup>

A new, comprehensive concept will only be suitable in the paediatric setting if it can encompass the many different expressions of spirituality found amongst the diverse population who use the healthcare service. Spirituality and religion can be viewed from this new conceptual perspective and can be synthesised by relating them to the impact on the context. In this way, I hope to distance myself from any fixed value-based system and avoid prejudices and judgments, while embracing the diversity of human expression of meaning.

I disagree with Nye, when she states that:

Attempts to define spirituality closely, and derive an adequate operational definition can be sure of one thing: misrepresenting spirituality's complexity, depth and fluidity. Spirituality is like the wind – though it might be experienced, observed and described, it cannot be

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<sup>50</sup> In 2002, when the Scottish Executive issued its 76th Health Department Letter (HDL) of that year, entitled Spiritual Care in NHSScotland, the agenda for health and spirituality possessed a document that would broaden the understanding of spiritual and religious care

captured – we delude ourselves to think otherwise, either in design of research or in analytical conclusions (Nye in Reich, Oser and Scarlett (eds.), 1999, p.58).

This is a surprising comment given that Nye has attempted to define the term. The analogy may overstate the point as my aim is not to ‘capture the wind’ but only to attempt to measure some aspects of it; although I may not be able to locate spirituality per se, I will attempt to understand the impact it has on an individual in a particular context . A weather forecast may not be able to predict the outcome of weather systems but it does give some indication of expected impact and allows for the planning of a response. Spirituality can, in different contexts, mean different things and have a different focus. In education, it might be used to refer to spiritual reflection, whereas in social work and healthcare it might relate to people’s state of well-being. In a religious context it might be used to describe experience or transformation. If it is possible to devise a conceptual construct through which to understand children’s spirituality in a paediatric setting then, far from Nye’s suggestion of delusion, the result would be potentially insightful and beneficial in how it relates to the delivery of care by a professional to a patient. Identification of this conceptual construct will provide the flexibility to devise an operational definition which can form the basis for the development of an interpretative framework of spirituality.<sup>51</sup>

In order to understand patients, a single interpretative framework should encompass the multidimensional descriptions employed by a variety of professions. The framework should not focus on the source of spirituality but on how people interpret their spirituality in a context which challenges their sense of meaning (Carroll, 2001, p.94; Narayanasamy, 2002, p.1469; Taylor, 2006, p.734). It should not be beyond the skill of any healthcare professional to assess the importance of a child’s narration of the meaning of their spiritual experience and be able to describe, in terms that can be clearly understood by other staff, what that might mean for the delivery of care to that patient. The concern is not to verify the basis of their spirituality but to identify one dimension in which they use such a belief system as a helpful means of coping with their situation. A conceptual construct which explains what that

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<sup>51</sup> In terms of operational this is not in the same sense as how Chui reviewed studies that were operational because they were measurable (Chiu et al., 2004, p.417). This thesis is not using a measure to identify spiritual needs of children. There are criteria set out in the chapter focusing on competences but this is observational rather than measurable.

connection is, and facilitates communication between a multidisciplinary team, will be a powerful tool.

In the search for an appropriate conceptual construct to describe children's spirituality in a healthcare setting, consideration must be given to how such a construct relates to the developmental stages of children and to how spirituality might be presented at these stages. By exploring theories of child development we gain a vantage point from which to view aspects of spirituality which would otherwise be obscured by overly broad conceptual constructs. Two areas require further consideration if a concept of spirituality is to provide robust insight in a paediatric setting: how does a healthcare chaplain discover this information; and how can we explain what this means in relation to children of different ages? This project will address these questions by discussing how Spiritual Assessment Tools (SATs) can be used by a healthcare chaplain to gather information from paediatric patients and by examining how the information collected corresponds to stages of child development.

It is premature at this point in the thesis to suggest a replacement for the term "spirituality" and as such the presence of the term "spiritual" in the thesis question may appear to be misleading. However, given that one of the approaches adopted by healthcare professionals, and particularly chaplains, is the use of a Spiritual Assessment Tool (SAT),<sup>52</sup> the inclusion of the word "spiritual" indicates a conceptual assumption on the part of those who have used such tools.<sup>53</sup> At this point I consider it to be premature to change the terminology and while there is merit in maintaining the status quo to avoid confusion, there will come a point in this thesis where the term "spiritual" will be replaced with another conceptual term. My project aims to introduce a Spiritual Assessment Tool (SAT) supported by a conceptually strong structure which relates well to children. If achieved, a revised name may be proposed but the established term, SAT, will be adopted throughout this thesis to avoid confusion.

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<sup>52</sup> An outline of available SATs are described at a later stage

<sup>53</sup> The specific responsibility of the professional in using an assessment tool is to identify connections, religious, spiritual or other, and then to reflect on their own involvement in the process.

## **H. Chapter Summary**

This chapter proposes that a clear insight into the spiritual needs of hospitalised children is required and notes that no study within the UK has focused on children in this specific context. If the concept of spirituality is to be applied in any meaningful way, then a conceptual construct relevant to the paediatric context must be devised. The concept must also enable multidisciplinary staff to understand and effectively describe the needs of children. This new conceptual construct will provide the interpretative filter required to more clearly identify the wide spectrum of understandings of the term spirituality and do so in a format accessible to a generation not familiar with the religious concepts of the past. The current framework used by government legislation for spiritual and religious care is insufficient and an interpretative framework is required which can enable professionals to communicate with each other. It must be consistent with the dynamics of communicating with children and have the conceptual integrity to ensure professionals can engage with children in a competent manner.

## **Chapter 2: Insights from developmental psychology; contributions to the criterion required for a new interpretative framework that describes childhood spirituality.**

No one theory has it all. Such structures are helpful, for they give us ways to think and talk about young children and their families in our personal and professional lives (Myer, 1997, p.4).

### **A. Introduction**

Chapter One argued that there is insufficient insight into how to understand and appropriately describe the spiritual needs of hospitalised children and established the need for the development of an effective conceptual framework. Two key factors this conceptual framework should consider are the displacement of children from their usual context and the nature of child development (Rodgers, 1989, p.332). In considering the importance of these factors, this chapter will examine evidence from the field of developmental psychology, which is based on observation, research and theoretical analysis of the developmental stages of children.

This chapter will:

- outline attempts to address childhood spirituality which have been made through childhood development theories, relating these to the paediatric healthcare context
- explore how child development studies can shape a more detailed interpretative framework of spirituality and offer building blocks to create a new conceptual construct.

Insights from developmental theories are combined to offer details of the appropriate processes, descriptions and environments required to understand the conceptual framework and to provide the working definition required to identify what is currently referred to as 'childhood spirituality'. As children move through developmental stages they manifest increasing capacity to rationalise, relate socially and appreciate their surroundings in different ways. As such, the spectrum of ages within this study (ages 6-13) will be explored through

child development stage theories which have previously been applied by healthcare professionals in an attempt to understand the concept of spirituality in children. These theories include work by Piaget, Erikson and Fowler. Their insights into child development are then complemented by the environmental and contextual dimensions of Bronfenbrenner's Bio-Ecological Theory, in order to offer a broader and more robust conceptual structure that illustrates the complexities of childhood spirituality.

## **B. Introduction to developmental psychology theories**

Committing to a search for a new conceptual framework of childhood spirituality is the first step in finding the most appropriate way to explore spirituality in a paediatric context. The field of child development has the capacity to aid understanding of the "spiritual response in children" (Pehler, 1997, p.56). If healthcare professionals can identify the spiritual needs of a child, they will be better equipped to offer appropriate care. Pehler's 1997 study entitled "*Children's Spiritual Response: Validation of the nursing diagnosis spiritual distress*" selected a definition of spirituality which was applied to gain insight into the response from healthcare chaplains to what they experienced as they conducted their work with children and their families. The study made a connection between spirituality and illness through Attribution Theory,<sup>54</sup> focusing on existential and experiential dimensions of spirituality in situations where children were observed asking existential questions such as "why?" Observations were made in crisis situations, such as during diagnosis of serious illness or after serious injury, where Pehler recorded how children manifested their views, behaviour and feelings to healthcare professionals who, in turn, relayed their interpretation of the children's spirituality.

Pehler's study was influenced by Piaget's Cognitive Developmental Theory and Erikson's Social Development Theory and provides an example of a healthcare professional utilising developmental psychology in an attempt to understand childhood spirituality (Pehler, 1997, p.57). It is important to consider why these theories are used and to evaluate the insights they offer; to ascertain their limitations and establish the extent to which other theories may provide further insight into childhood spirituality.

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<sup>54</sup> In the attribution theory she acknowledged that it was inconclusive as to whether or not children attributed these to external or internal factors. The main point was that she considered that these factors corresponded to the developmental stages of children

## *1. Piagetian Theory*

Piagetian Cognitive Theory has had a fundamental impact on the field of developmental psychology. It has provided significant insight into the cognitive development of children up to the age of 12, and has often influenced the work of healthcare professionals attempting to understand the spirituality of hospitalised children (Hood in Ratcliff (ed.), 2004, p.234; Ratcliff and Nye in Roehlkepartain et al. (eds.) 2006, p.475).

### *a. Outline*

Piaget's theory maps out the developmental stages of a child from infancy to age twelve. Passage through the stages of development is summarized by Hart as moving from "the very body-based knowing of an infant to increasing abstraction" (Hart in Roehlkepartain et al. (eds.), 2006, p.168). The premise of Piaget's theory is that a child builds up knowledge or capacity to think in parallel with biological development (Beilin in Vasta (ed.), 1992, p.86). The development of a child is understood through conceptual stages which are divided, according to steps of knowledge, into a logical progression. Progression to a higher stage assumes that knowledge from the earlier stages is established and the order cannot be reversed. So in order for a child to understand algebra, they would need to have a knowledge base of arithmetic (Gorsuch and Walker in Roehlkepartain et al. (eds.), 2006, p.95).

Piaget proposes a link between a child's cognitive and biological development. He acknowledges the importance of physical knowledge gained through experience in addition to knowledge which processes and organizes (Beilin in Vasta (ed.), 1992, p.86). Cognitive development is seen as a process of revision or "adaptation", with children tending to organize their cognitive structures into efficient systems. Piaget identifies two processes within this adaptation and reorganising. The first process is "assimilation", where current cognitive schemes are used to interpret new knowledge. The second process is "accommodation", where old cognitive schemes are adjusted to better fit the child's environment. Piaget refers to the balancing of these processes as "equilibrium", where the cognitive structure is made to fit better with the child's current physical and social setting, for instance, when a child visits another child's home for the first time. Significantly, the process of assimilation "provides the basis of meaning, in that all knowledge is arrived at by assimilation, from the most primitive perceptual signals to conditioned responses" (Beilin in Vasta (ed.), 1992, p.87). Children constantly attempt to make sense of their world so they are more able to engage with it. The way in which children do this is referred to as being their

cognitive style; a concept that indicates that a child's particular "library" of existing knowledge and experience can result in different resources of thinking, which can then manifest in different ways, with individual children using alternative avenues to reach a sense of equilibrium.

Piaget identifies universal invariant stages of child development which closely correlate with the biological development of human beings. Whilst acknowledging that the process of development is continuous, he establishes several discontinuous theoretical stages:

1. Sensorimotor stage (birth – 2 years) – Object permanence is the goal
2. Preoperational stage (2-7 years) – The growth of representational abilities
3. Concrete operational stage (7-12 years) – The ability to think using mental operations
4. Formal operational stage (12 years and over) – Reasoning through propositional, abstract and hypothetical ways - Hypothetico-deductive reasoning.

The sensorimotor stage occurs between birth and 2 years old. During this stage infants depend on their senses to comprehend their surroundings, for instance, when a baby reaches out to touch an object. The preoperational stage occurs between 2 and 7 years old and during this stage children make sense of the world, not just through their senses, but also through the use of words and pictures. Pre-operational refers to Piaget's proposition that children at this stage are not yet able to "perform operations, that is, mental operations that are reversible" (Santrock, 1989, p.167) and they still require physical prompts to generalise from the specific. Using existing knowledge to relate to other objects, children at this stage may understand the shape of the moon because they have an idea of a ball. The concrete operational stage occurs between the ages of 7 and 11, by which time children are able to perform certain tasks and understand why these operations work. At this stage children have the capacity to calculate addition and subtraction but would not be able to understand the more abstract procedures involved in algebraic equations. The formal operational stage occurs beyond the age of 11, when children have the capacity to use logic and understand more abstract concepts. At this stage children would possess the capacity, for instance, to comprehend the abstract concept of 'good parenting'.

### *b. Insights*

Piaget's cognitive theory is relevant to describing the spiritual needs of children, as it encompasses and goes beyond the stimulus and response process approach of biologically based conditioning theory and asserts that children are active agents in their environment. If, as Piaget proposes, a human being has the capacity to assimilate experience and respond based on their understanding of that experience, then it follows that a child's past experience can shape the way they approach a new situation. Such insight into how children might perceive their immediate surroundings has important implications for this project. For example, if two children of different ages are admitted to a hospital for the first time, Piaget's theory would suggest that each child could draw only from their past experience and that their cognitive processing of this similar situation could therefore have very different outcomes. The combination of biology and experience in Piaget's theory provides an understanding of the way in which they combine to develop children's cognitive ability, enabling them to meaningfully engage with their environment.

Piaget's approach may indicate why children find it hard to come to terms with their immediate circumstances if in attempting to do so they reach a conclusion that makes them feel alone and therefore distressed. This can become especially relevant when a child is displaced from one familiar context to an unfamiliar one, such as a child's first experience of admission to hospital. Piaget uses the term "object permanence" to describe the stage when a child is able to comprehend that an object still exists even though it is out of view. "Egocentrism" refers to the stage when a child is unable to contemplate the perspective of others. Donaldson, a student of Piaget (and later critic), describes egocentrism as the child's inability to "de-centre" in their imagination (Donaldson, 1978, p.20). The child is only able to describe what they think another person sees from their own perspective. A child may know that the perspective changes when they move, but are unable to transfer that into their explanation. This is summarised by Donaldson as a child holding to "false absolutes" (Donaldson, 1978, p.20). The child takes their own perspective and concludes that this is also others' reality. For example, a child who is returning to hospital and who has developed into a new stage may need less parental clarification about this return visit, not because of previous experience but because they now have the cognitive ability to dispense with their previous perspective of the hospital with an attitude that is consistent with their development.

### c. Critique

Although potentially useful, difficulties can emerge when attempting to apply Piaget's theory. There are two main criticisms from within the field of psychology itself, and from those who use psychology to understand children's spirituality. Questions have been raised on Piaget's methodology<sup>55</sup>, the cultural limitations on the application of the theory<sup>56</sup> and on the inappropriate construction of theory<sup>57</sup> in terms of the absence of children's spirituality. The latter source of criticism is the primary focus at this point in the thesis. Those who have sought to use Piaget's theories as a means to understand childhood spirituality have also made significant criticisms of his work.

#### (i) Lack of awareness of spirituality

Nye notes that developmental psychology literature makes little mention of spirituality in childhood (Nye in Best, 1996, p.108), although it should be noted that Piaget's theory emerged before spirituality was discussed using the current terms of reference. Hart raises similar questions, and in making reference to a child who asks his father 'Why are we here?' Hart notes that even though children may not be able to articulate and express certain life

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<sup>55</sup>Piaget's methodology has been criticized because he used the very small sample of his own children within a laboratory setting, where, it can be argued, the behaviour of children might be different to that of everyday life. However, further studies with larger samples and in different settings have resulted in similar findings. Current models of thinking that take a child's context into consideration are propounded by social cognitive theorists such as Dodge who contextualizes Piaget's schemata as building blocks of knowledge. "He emphasizes the fact that schemata are stable mental structures which incorporate children's perceptions of self, their experiences in the past, and their expectations for the future" (Wenar, 2000, p.11). This cognitive style is consistent with the view today where, rather than the classic Piagetian view which considered young children as irrational and prelogical, children are now considered to be "adept at handling different systems of thinking about reality." (Keenan, 2005, p.29). One such system was the "default system". It "rests on direct observation and on an innate push to find patterns and causal connections." (Keenan, 2005, p.30).

Donaldson (Donaldson, 1978, p.21) questions the effectiveness of Piaget's work in a comparison between Piaget's *three mountain* experiment<sup>55</sup> and Hughes' *policeman* experiment, which consisted of a child trying to describe the different view of two doll policemen of two intersecting walls. The purpose of these experiments was to test children's ability to comprehend a scene from a different perspective. Hughes' experiment produced results that would suggest that developmental stages set by Piaget should be earlier as children appear to have better cognitive abilities than Piaget concluded. Donaldson accounted for this variation by suggesting that children are able to ascertain a different perspective through what "makes human sense" (Donaldson, 1978, p.24). In Piaget's experiment, it was hard for the children to understand what they were supposed to do. However, although perhaps with appropriate stimuli, children can comprehend at an earlier age than Piaget suggests, this does not negate the cognitive stages that Piaget defines.

<sup>56</sup>Burman contends that, "Piaget's theoretical framework privileges masculine and Western forms of reasoning, stigmatising and dubbing as inferior the irrational." (Burman, 1994, p.160). She considers that insufficient attention is given to other significant aspects of development, such as emotional intelligence. These are important points to consider but as the focus of this thesis is set in Western society, Piaget's findings would still be relevant in the context within which the children will be recruited, although the aspect of gender will not be addressed (see EAUDE, 2004, p.53). This would need to be addressed further if this thesis was to be considered in other non-western settings where other psychological theories have been developed.

<sup>57</sup>Vuyk understands Piaget's theory to imply that there is a rest period or time of equilibrium between each developmental stage (Beilin in (ed.) Vasta, 1992, p.89). Piaget did not intend this implication; he did not place much importance on this feature of his theory although it was retained in his work (Beilin in (ed.) Vasta, 1992, p.86).

issues, they are revealing these concerns in other ways that can complicate and potentially contradict Piaget's evolving staged theory (Hart in Roehlkepartain et al. (eds.), 2006, p.168). As such, it is important to acknowledge that spirituality was not Piaget's immediate focus.

*(ii) Religion rather than spirituality*

Ratcliff<sup>58</sup> examined studies conducted in the 1990s which used Piaget's theory of child development to understand the spirituality of children, finding that researchers tended to use the theory in a way which focused on "thinking about religion rather than the experience of religion" (Ratcliff and May in Ratcliff (ed.), 2004, p.11). Thinking about religion might be relevant to a child's education, whereas the experience of religion has a closer affinity with the concept of spirituality. This project is primarily concerned with how children's knowledge of religion is related to their experience, and what their response to that is, rather than their ability to articulate their knowledge of religion. It is their spiritual dimension that is of immediate concern rather than their religious development per se.

Nye also noted that Piagetian theory is used in research, like that of Ronald Goldman<sup>59</sup> (Nye in Ratcliff (ed.), 2004, p.92), where the focus is on the accumulation of religious knowledge rather than on experience. Nye suggests that to perceive childhood spirituality only on a cognitive level necessarily diminishes the spiritual capacity of the child in the mind of the researcher. Applying Piaget's theory to assess a child's ability to articulate such a specific concept as his understanding of God highlights that the theory is restrictive to the point of irrelevance. This is not a criticism of Piaget's theory itself, but illustrates the limits of its application to the study of childhood spirituality. Clearly, Piaget's cognitive theory has something to contribute but, just as it addresses only one aspect of the cognitive dimension of the child's development, so it also plays only a partial role in understanding childhood spirituality. Hood warns of the additional danger in using Piaget's theory to examine children's spirituality; as it results in children being framed in comparison to adult cognitive ability, this may result in a misunderstanding of childhood spirituality (Hood in Ratcliff (ed.), 2005, p.234).

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<sup>58</sup> Donald Ratcliff is the Price-LeBar Professor of Christian Education at Wheaton College

<sup>59</sup> Ronald Goldman played an influential role in the Christian education of children in the United Kingdom

*(iii) Separation of emotional and intellectual aspects*

Fowler<sup>60</sup> highlights Piaget's focus on a child's cognition and reasoning, rather than their experience of emotion and attachment, and offered no integrated understanding of how different aspects of reasoning and emotion might relate to each other (Fowler, 1995, p.101). Fowler distinguishes between what he describes as Piaget's understanding of cognition as the "logic of certainty" with that of his own term, "the logic of conviction" (Fowler, 1995, p.102). In doing so he indicates a common characteristic between them, that of a "reconstitution of the knower in relation to the known" (Fowler, 1995, p.103). Fowler proposes that a change takes place when individuals gain knowledge or belief that was not present before and as a result takes issue with the small value which Piaget accords to the place of imagination in the child (Fowler, 1995, p. 103). Piaget does not consider the imagination as a means to explore beyond what is a rational reality. However, Fowler does not agree with Piaget that the imagination is merely "childhood fantasy"; a precursor for the intuitive child in the preoperational stage; but argues that it is part of the child's spiritual development and continues to be part of an individual's construction of faith.

*d. Application*

For the purpose of this study it is necessary to consider the cognitive developmental capabilities of children in order to formulate a new conceptual construct that is applicable to them. Piaget's theory is useful in providing an understanding of how children perceive their world and make judgements in relation to their stage and experience. However, given that it takes no account of emotional and social factors, the scope of the theory means it is inadequate for the broader study which I intend to undertake.

However, Piaget's theory was informative when selecting the age spectrum of the sample for this study. It provided a framework to assess the cognitive ability of the children selected, allowing for consideration of the relationship between cognitive ability and the manner in which the data should be gathered.<sup>61</sup> If a group of primary school-aged children were

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<sup>60</sup>Charles Howard Candler Professor of Theology and Human Development at Emory University, was director of both the Center for Research on Faith and Moral Development and the Center for Ethics until he retired in 2005

<sup>61</sup>In terms of methodology those at the formal operational stage use hypothetical-deductive thinking and can reach conclusions not based on actual observation. So the children in the study are able to think things through by using mental operations. They are able to work alongside other children, in a collaborative or competitive manner. They are able to ascertain a concept of fairness in their social interactions. They can use a basic level of logic to manage physical objects or work through experiences. This is important as the SAT used takes the form of a card game and storyboard to enable children to work through their thinking and experience.

interviewed, the primary focus would be on the “concrete operational” stage. Even though primary school age children may still be in the “preoperational” and “formal operational” thinking stages, those still at the preoperational stage would likely be at the higher end of this stage; formulating language and beginning to form naive perceptions. Those in the concrete-operational stage would, according to Piaget, use reason although they deduce this from the concrete reality of the present:

Thinking at this stage depends heavily on the actual context; there is an emphasis and reliance on strict rules and literal interpretations.

Development of some control over the operation of thought processing begins. Children now begin to appreciate logical explanations and connections between things; they are sensitive about whether things ‘make sense’. Children at this stage can make rational judgments and be objective only in terms of what appear to them as the literal, ‘concrete’ features under consideration (Appendix 7).<sup>62</sup>

However, we should be aware that Piaget’s theory does not address the attitudes adults might have to how children perceive their own reality. When meeting a child for the first time it may be difficult for a healthcare professional to ascertain a child’s developmental stage. This is especially difficult when the child is out of their normative context, is unwell and when their physical condition may be affecting their level of development.

Piaget’s theory has relevance to the study of childhood spirituality in relation to how children construct meaning through their “cognitive style”, whether through contact with a parent or attachment to belief in a god-figure. Using Piaget’s theory, children’s manner of expression can be seen as being related to the level of communication appropriate for their

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<sup>62</sup>In Appendix 7 I decided to collate such professional summaries from different psychological theories in order to make a comparison between them. This was helpful in terms of stage theories such as Piaget, Erikson, and Fowler, but this exercise was not accommodating to Vygotski. The developmental presentation of stage theories have a linear dimension that is suitable for descriptive information to be placed on a table of contents but Vygotski’s work does not have the same dimension as it’s focus is much more process orientated and contextual. The outcome of this exercise alerted me to the limitations of such a process as it restricted the perspective of a healthcare professional to the cognitive and biological dimensions used by these developmental psychology theories. Therefore, it is evident that some healthcare practitioners can turn Piaget’s cognitive theory into a technique to try and understand the spiritual needs of children. However, an over dependency could result in a healthcare professional being too prescriptive in the spiritual care needed. In Piaget’s theory other cultural and historical factors have not been taken into consideration and how these might impact upon the whole child. The theory he presents is helpful in understanding the development of the child’s mind, but to select this one cognitive dimension and make this a definitive characteristic is to go beyond what Piaget had intended. The findings are helpful but were not designed specifically for this purpose and caution is required in its application.

developmental stage. However, their limited manner of expression cannot be assumed to be an indication of limited spiritual capacity. It is not *their* incapacity to express themselves that is the problem; rather the problem is with *our* limited capacity, as adults, to understand children's communication and our limited appreciation of why children communicate spiritual needs in a particular way.

A comprehensive insight into childhood spirituality must explore more than a child's cognitive ability to bring meaning to the world. Assessing the cognitive capacity of the child merely places a child's developmental level relative to other children of similar age (Flavell, 1992, p.1000). Different levels of cognitive ability do not necessarily mean greater or lesser spiritual capacity and this will be explored further through the lens of other psychological theories. Given that Piaget proposes that children's adaptation to the environment occurs through the psychological processes of assimilation and accommodation, the user of the spiritual assessment tool (SAT) may use these concepts to observe the hospitalised child's equilibrium. However it is difficult to comprehend what it is that is spiritual about this balancing process. If assimilation involves a child using current schemes to interpret new knowledge, and accommodation involves the adjustment of existing schemes to more effectively fit a new environment, then this linear process should become a defining feature of how a new construct of spirituality should consider the way a child creates meaning in new or changing circumstances. In creating meaning, the child reviews past experience when connecting with a new set of circumstances and adjusts their perspective to project a new outlook on an imagined future. In going through this process, a hospitalised child may need to make a series of adaptations in moving from the familiar to the unfamiliar and this may result in the child feeling fragile or even volatile. However, awareness of this process does not assist in identifying what aspects of a child's past experience might trigger such a process. It would be helpful to explore further the content of children's lives when at home to discover the type of thoughts they have about the future in order to sustain their equilibrium whilst in hospital. This may frame the meaning-making process; for example, what does a child think about hospital once admitted to it compared to their previous expectations formed in their home context?

An important emerging feature for the development of a new construct of childhood spirituality is that of cognitive style; the ability of a child to think through their changing circumstances. In terms of the biological dimension of Piaget's theory the ability to survive is

critical to the development of the child. In an educational setting the focus is on optimising children's learning experience, but in the healthcare setting the focus is on recuperation. A child's cognitive style becomes more evident during the cognitive conflict which emerges when a child predicts a certain outcome which is not achieved, leading to a clash in the child's mind between two inconsistent realities. In an educational context this clash may be important in facilitating new learning and might be welcomed by a child who wants to work things out like a puzzle. However, when this conflict relates to experience of pain, or dashed expectations of going home from hospital, then the child requires a certain level of cognitive ability to work through these difficulties. However, it may be more difficult to ascertain a child's cognitive style in a paediatric setting as the collaboration of parents and carers may obscure it. Although cognitive style explains the process of how children use existing knowledge and experience adapt to a new environment, further consideration needs to be given to how children make such connections in order to construct meaning. This is not addressed by Piaget.

Donaldson (1978) highlights a possible tension between enabling a child to cope with the immediate circumstances surrounding recovery from illness and the longer-term goal of assisting a child to become independent. She notes that it is difficult to achieve both without smothering children's decision-making ability or leaving them feeling isolated. Donaldson's idea of "human sense" gives contextual balance to the cognitive dimension of child development (Donaldson, 1978, p.17). The idea suggests that a cognitive approach would work well for children if they were to express themselves with reference to a familiar context. The key indicator for a healthcare professional applying Piaget's theory alongside the SAT should be to identify with the children's level of familiarity with hospital surroundings to gain a sense of their equilibrium or disequilibrium. A sense of disequilibrium, or imbalance, in the child might give rise to spiritual distress which may be affected by the ability of the child to develop a cognitive style that is in touch with familiar or unfamiliar surroundings. Piaget's theory should not be reduced into a restrictive technique. The theory is useful to aid understanding of children's cognitive abilities, but falls short of providing a comprehensive foundation for an appropriate approach to spiritual care.

In summary, Piaget's cognitive theory is useful in that:

- It provides a framework through which to relate children's cognitive capacities to age and stage of development.
- It enables healthcare professionals to understand a child's perspective and why a child may decide or behave in a particular way.
- It encourages professionals to engage with the child in a manner that is comprehended by the child.
- A new construct to describe the spirituality of children would identify how children are affected by their immediate surroundings, taking into consideration their developmental stage. This would manifest itself if, for instance, a younger child finds a doctor to be distressing but only when the doctor is present, whereas an older child might be affected by thoughts of a doctor even when not present because the child is able to anticipate the doctor's return. In both cases, there is an aversion to making a connection with the doctor, but it is processed differently depending on the stage of the child and past experience. Healthcare professionals who are aware of this would adjust their approach to the child accordingly.
- It introduces the concept equilibrium; a child's "state of the moment", described by Piaget as being like a slow motion film (Donaldson, 1978, p.20). A hospitalised child may find it difficult to reach equilibrium, and instead become distressed.

## 2. Erikson

Piaget provides insight into the cognitive development of the child only up to the age of twelve, examining how a child's cognitive capacity contributes to their perception of their environment in order to create meaning. Erikson studies the complete lifespan when addressing social development.

### *a. Outline*

Psychologist Erik Erikson's work was based on Freudian psychology, although Erikson considered social development to be more significant than the sexual issues emphasised by Freud.<sup>63</sup> Erikson espoused the epigenetic theory of psychosocial development in which a person's successful development depends on the presence of an appropriate social and

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<sup>63</sup> Halstead and Waite (2001) have sought to address the connection between spiritual and sexual development

cultural nurturing environment where the inherited natural plan may flourish.<sup>64</sup> Through the use of individual case studies, in particular the life of Gandhi, he introduced the Life Cycle Theory in 1965 with its “Eight stages of Man”. In his “triple book keeping” concept he identified three key factors that affect the life and behaviour of an individual:

- the “somatic” factor which relates to the physiological aspect .
- the “ego” factor; how an individual makes sense of themselves in relation to the world through reasoning and understanding.
- the “societal” factor; the relational aspect of a person’s life such as family, friends or school (Lyll, 2001, p.109).

The interaction between these three factors complements the dialectic interaction between individual development and socialisation which results in “cog-wheeling” or “developmental dialogue.” For Erikson, child development is dependent on and determined by this interaction (Myer, 1997, p.8). Related to this, Erikson refers to faith when he describes hope in terms of “the ontogenetic basis of faith ... nourished by the adult faith which pervades patterns of care” (Erikson, 1964, p.118).

The tension in the interactions between individual development and socialisation is conceptualized by Erikson in a series of stages related to the human life span. Individuals have the potential to experience optimal growth at each stage. However, if the positive route through the interaction is unsuccessful at any one stage, this could then result in the carrying of unresolved outcomes from one stage to the next (Templeton and Eccles in Roehlkepartain et. al. (eds.), 2006, p.259). This tension is reflected in the descriptions of the eight discontinuous stages covering the life span of an individual:

1. Trust vs. mistrust (Birth – 1)
2. Autonomy vs. shame and doubt (1-3)
3. Initiative vs. Guilt (3-6)

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<sup>64</sup> The inherited natural plan is the interplay between the associated features of a particular social stage e.g. Trust vs. mistrust. The feature associated with this stage is what is present in the natural plan but the balance of the two is affected by social and cultural nurturing and in turn will affect the following stage of what is in the natural plan.

4. Industry vs. inferiority (6 – adolescence)
5. Identity vs. identity diffusion (12-20)
6. Intimacy vs. isolation (20-40)
7. Generativity vs. stagnation (40-60)
8. Integrity vs. despair (60+)

(Watts, F.; Nye R.; Savage, S, 2005)

A new stage may emerge when individual development does not match the demands of the social context (Templeton et al. in Roehlkepartain et al. (eds.), 2006, p.259). Erikson referred to this as a crisis, marking a turning point in individual social development.

#### *b. Insights*

Erikson's psycho-social development theory highlights the potential tensions experienced by individuals in a given context. A particular context, such as a hospital, may remain the same but a person's social development can affect how they relate to that unchanging context. For example, some children may cope better than others in the hospital context as a result of their more advanced personal development.

Each stage title describes the predominant characteristic of that stage. In the process of individual development, prior stages are still present and so contribute to, or detract from, the success of the current stage. For instance, the fourth stage of 'industry versus inferiority' addresses how children's interest in how things work might be positively developed by encouragement, or negatively developed when perceived by others as creating a mess. Experiencing negative feedback, the child develops feelings of inferiority which play a significant part in the capacity for development in the next stage. As a result of these tensions between individual development and socialisation, Erikson suggests that the combination of a change of context and a child's transition into a new stage might bring about an identity crisis. Santrock states that "this confusion can take one of two courses: individuals withdraw, isolating themselves from peers and family, or they may lose their identity in the crowd" (Santrock, 1989, p.395). This theoretical approach gives rise to questions such as, "Is the child developing a sense of mastery over aspects of their environment and coping with challenges of increasing responsibility? Is he mastering intellectual and social challenges? Is he developing a self-identity?" As such, it provides a useful theoretical approach to pursue further insight into children's experience as they develop and interact with their surroundings.

### c. Critique

The adoption of this theory on its own in a healthcare setting, in my view, would have limited utility in terms of exploring children's spirituality. Healthcare professionals using this theory as a basis for investigation explore only one dimension of a child's spirituality in a healthcare setting (Ford, 2007; Hart and Schneider, 1997; Burkhardt, 1991; p.33). There are several reasons for this:

(i) Erikson presents a normative structure to understand development but the low level of flexibility he allows for anomalies compromises the integrity of his theory<sup>65</sup>.

(ii) Erikson's theory implies an inherent value system which suggests that an unresolved conflict is a failure to achieve or realise the virtues associated with each stage. The use of the term "virtue" by Erikson perpetuates this value-based outlook. Lack of achievement is then identified as a problem which might emerge in the individual later on.<sup>66</sup> The value system intrinsic within this theory has led to it being used in particular contexts, such as counselling, to address behavioural difficulties. However, in the context of this thesis assessment must be considered as non-judgemental observation, giving respect to the status of individuals and their choices. The presence of illness, and its impact on individuals, may lead to the disruption of the developmental stages to the extent that they become unrecognisable. The purpose of gathering information through use of a SAT is to ensure that appropriate spiritual care, not therapy, can be offered. Applying a theory with a longitudinal focus in an acute setting, such as paediatrics, suggests that the assessor might have a limited insight into the social factors affecting a child. As such, caution should be exercised when using this theory for assessment purposes.

(iii) Associated with the problem of the value based outlook is the potential that when a judgement is made, it can be disempowering for those subject to that judgement. There is a danger of engendering a feeling of inadequacy by asking an individual to contemplate

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<sup>65</sup>One of the dangers of this stage theory is that it confines the characteristics of a particular stage to that stage alone and does not associate those features with any stage outside of the age range that Erikson has attributed it to. Erikson, himself, concedes that the eight descriptions highlight the *prominent* features of each stage, not the *only* ones which create the conflicting tensions described by Erikson. If these characteristics extend outside of the given stages, does the description of each stage accurately reflect how a person is actually developing? Does the stage correspond with what an individual is experiencing at a particular age?

<sup>66</sup>To apply such a value-based theory would make a SAT a more therapy-orientated tool rather than a diagnostic observational instrument. This is discussed more fully in Chapter 2.

their lack of development, or if such an analysis is reported to them.<sup>67</sup> The focus and assessment should be on the impact of the immediate context on the social development of the individual, rather than their level of development *per se*.

(iv) A difficulty in attempting to apply this theory to the assessment of a hospitalised child is that the theory is based on the dialectic interaction between the individual and their social context. The social context of the ill child may be significantly different from their normal context and it would be difficult to make an assessment which compares the hospital context with the child's context in the community. The application of this social development theory is specific, but still potentially useful in indicating how the balance at the child's current stage is affected during a stay in hospital. It may provide a window of insight into an important dimension of the child's social development. Therefore, it would be appropriate to use the theory as a basis to discover how children perceive and understand their current context through their descriptions of the wider context of their lives in the community. However, this would not be achievable using Erikson's theory alone, as it focuses on a longitudinal view of individual development whilst the assessment focuses on the individual in the immediate hospital context. This is further complicated by the experience of a new social setting and the physiological impact that illness or injury might have.

#### *d. Application*

Erikson's theory only partially overlaps with the age spectrum of this study, describing three stages of development that are relevant; the latter part of Stage 3 (ages 3-6), all of Stage 4 (ages 6- adolescence) and the start of Stage 5 (ages 12-20). Within a confined social setting, such as a hospital, it is difficult to know how Erikson's theory can be applied. In terms of the Industry vs. Inferiority stage (from 6 years to adolescence), a hospital experience may be atypical of what children generally experience at this stage and a hospital stay may potentially result in a premature move to a new stage. It could also be that a hospital experience engenders an unhealthy imbalance in a child's development which may delay the full achievement of the next stage of social development. For example, a child may initially feel deprived of being industrious through enforced inactivity in hospital, and as a result may experience a sense of inferiority. This may be especially significant for a child who has a chronic condition requiring repeated hospital visits. An interpretation of the child's social

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<sup>67</sup> Or, in the case of paediatrics, to the parents/carers as well

resilience based only on Erikson's theory may confuse an assessor's view of a child's difficulties, unless the assessment identified how this situation could be avoided or at least mitigated.<sup>68</sup> Otherwise, the focus would be on the detrimental impact a healthcare context has on a child's spirituality. Therefore, the next building block for a new conceptual construct is to assess the stability and cohesive social dynamic of children in relation to their development.<sup>69</sup> It is important that the assessment identifies the impact of children's social dislocation and how that dislocation might positively or negatively affect their development as they negotiate their social context at their stage of development in terms of what they had previously imagined themselves to be.

In the context of this thesis it is important to consider the usefulness of development and stage theories in relation to children who may have life-limiting conditions and whose long-term quality of life is affected. In my view, Erikson's theory used alone has limitations in such a context. An assessment framework for understanding a child's spirituality shaped predominantly by Erikson's theory may engender a fatalistic attitude in the child as a result of their circumstances and the healthcare professional's questions.<sup>70</sup> However, appropriate application and sensitive framing of questions may allow for a measure of children's own sense of value in relation to their surroundings, which in turn might offer insight into their sense of social development. The challenge is to create a framework where the child is able to take ownership of their sense of social development, whilst working in partnership with the professional. A therapeutic response to the outcomes discovered through Erikson's theory could equip the professional with relevant data to offer appropriate care.

Erikson's theory offers landmarks for normative human social development and enables a professional to compare the social development of a hospitalised child with a child in the community. However, an assessment based on this theory should provide only a secondary reference point to indicate how children have progressed through previous stages and to indicate how well that progression has equipped them to develop socially through their healthcare experience. It cannot and should not be the predominant factor in addressing the

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<sup>68</sup> This does not address issues that might arise if a child has a life limiting illness how do the stages of Erikson correlate to this? Do they never experience them? Are they compressed into their lifetime? Would they understand themselves as an incomplete individual?

<sup>69</sup> There is the possibility that the healthcare context becomes a haven for social connectedness as staff may offer more stability than the child's home. This may be positive but when there is an over dependency displayed by the child, this aspect should also be picked up by the assessment.

<sup>70</sup> In terms of the SAT used in the interviews, the focus of the story and card games used would be too broad and would not address the immediacy of the child's current circumstances and change of context.

profile of a child's spirituality. For example, a hospitalised child within the age range of the fifth 'Identity vs. Identity Diffusion' stage could experience a loss of identity as a result of being away from their normal context. However, the child might feel more of a sense of identity being in hospital due to the amount of time spent there. The significance of social balance for positive development within these different contexts, and what meaning the child might draw from them, cannot be deduced from a single encounter with an assessor. Erikson focuses on internalised tensions but these may be distorted due to physical illness and mental tiredness. A researcher could use data which emerges from acknowledging the tension in this stage, to help children understand their sense of loss and helplessness. However, caution is required when applying this theory with limited knowledge of a child and their background, as it may be difficult to identify if the overt tension is due to the current setting of the child or to unresolved tensions from past experience. The professional must acknowledge that this dimension of assessment is quite specific in that the focus is on the impact of the healthcare context in relation to social development, and not on the longitudinal development of the child to that point.

Erikson's theory is appropriate for the purposes of a SAT only in a very specific way; for a healthcare professional to ascertain how the social development of children interacts with the impact of their healthcare context and their health condition. Applied to this thesis to create another building block for the conceptual construct of a child's spirituality, it can identify the internal dialogue children engage in to ensure the presence of a meaningful social balance that contributes to their development. An assessment would be observing this dynamic in a child to assess the need to retrieve their social balance.

### *3. James Fowler*

Thus far, two building blocks have been identified that form part of a new definition of children's spirituality. The first, based on Piagetian Cognitive Theory, identifies the importance of children's cognitive capacities as they seek to familiarise with their surroundings. The second, based on Erikson's Theory of Psychosocial Development, identifies the effectiveness of children's internal dialogues in seeking to maintain their social balance, in the context of new and unfamiliar environments. However, viewed in isolation these theories are insufficient to fully encompass the complexity of child development.

### *a. Outline*

James Fowler has played an influential role in discussion defining spirituality through the use of developmental stage theories, and has presented and defended his Faith Development Theory for over three decades.<sup>71</sup> Fowler acknowledges the influence of Piaget, Erikson and Kohlberg<sup>72</sup> on his work (Fowler, 1995, p.39). He developed an understanding of faith by identifying characteristics associated with stages, similar to those developed by Erikson (Fowler and Dell in Roehlkepartain et al. (eds.), 2006, p.34; Fowler, 1995, p.272). His theory for understanding faith was first outlined in his 1981 book *Stages of faith: The Psychology of Human Development and the Quest for Meaning*.

Fowler defines faith as being:

People's evolved and evolving ways of experiencing self, others and world (as they construct them) as related to and affected by the ultimate conditions of existence (as they construct them) and of shaping their lives' purposes and meanings, trusts and loyalties, in the light of the character of being, value and power determining the ultimate conditions of existence (as grasped in their operative images – conscious and unconscious – of them) (Fowler, 1995, p.93).

The three key elements of this definition are the experience of the person; the expected shape of their ultimate reality; and the choices and behaviour adopted in relation to their ultimate reality or transcendent being. Fowler perceives that “the essential conventional pattern of faith is relational” (Fowler, 1995, p.7). This triadic relational connection that gravitates to an “ultimate concern” could be anything in people's lives; it is where they have placed their priorities and the values they use to support them (Hill and Killian, 2003, p.151; Tanyi, 2002, p.506).

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<sup>71</sup>This discussion continues in a chapter contained in, “The hand book of Spiritual Development in Childhood and Adolescence”, entitled ‘Stages of faith from infancy through adolescence: Reflections on three decades of faith development theory’ written by James W. Fowler and Mary Lynn Dell in (Roehlkepartain et al. (eds.), 2006, pp.34-45)

<sup>72</sup> Kohlberg's work was on the staged theory of the moral development of a child. Kohlberg does not play a significant part in the discussions of childhood spirituality. He is mentioned because he was a close associate of James Fowler.

Fowler expresses the dynamics of this “faith” when he says that:

Faith is not always religious in its content or context. . . . Faith is a person’s or group’s way of moving into the force field of life. It is our way of finding coherence in and giving meaning to the multiple forces and relations that make up our lives. Faith is a person’s way of seeing him or herself in relation to others against a background of shared meaning and purpose (Fowler, 1995, p.4).

Fowler takes the normally religious term “faith” and conceptualises it generically so that it can be applied in a universal manner. His concept of faith is defined as being greater than religious belief; religious belief being only one of many expressions of faith. As such, Fowler views faith as a universal quality not exclusively associated with religious communities. He describes faith as a “way of seeing” and as “an active mode of knowing, of composing a felt sense or image of the condition of our lives taken as a whole” (Fowler, 1995, p.25). It constitutes not just an orientation to information, but also contains “affectional significance”<sup>73</sup> (Fowler, 1995, p.26). This association of emotion with knowledge is a significant combination brought together by identifying images and metaphors that individuals may use to reinforce their faith perspective; including routines or religious rituals.<sup>74</sup> Fowler outlines four features that characterise the concept of faith. He asserts that faith can:

1. Give coherence and direction to persons’ lives.
2. Link them in shared trusts and loyalties with others.
3. Ground their personal stances and communal loyalties in a sense of relatedness to a larger frame of reference (King and Furrow, 2004, p.703; Mattis and Jagers, 2001, p.535).

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<sup>73</sup> Affectional significance has a close correlation with Bronfenbrenner’s molar activity and dyads. The investment of trust and faith that a child has in their image of absent contexts of which a child is most familiar has “affectionate significance” for that child.

<sup>74</sup> This metaphor could be ritualistic from a religious context or it could be an item brought from home to be with a hospitalised child. The item has a metaphoric significance

4. Enable them to face and deal with the challenges of human life and death, relying on that which has the quality of ultimacy in their lives” (Fowler et al., in Roehlkepartain et al. (eds.), 2006, p. 36; Callaghan, 2005, p.94).

These four criteria span the lifecycle of an individual’s faith and it would be important to understand how these criteria relate to children and how they are manifested.

Identifying faith as being strongly relational, leads to trust becoming a primary factor in understanding what faith is. This, in turn, affects individuals’ identity and how they understand and relate to others. Fowler identifies three “faith-identity relations”; polytheism, henotheism and monotheism. Using these terms in a generic way he removes them from the confines of religion and to a certain extent removes them from theism. Fowler defines polytheism as lacking “any one centre of value and power of sufficient transcendence to focus and order one’s life” (Fowler, 1995, p.19). He defines henotheism as being “a pattern of faith and identity in which one invests deeply in a transcending centre of value and power, finding in it a focal unity of personality and outlook; but this centre is inappropriate, false, not something of ultimate concern” (Fowler, 1995, p.20). Radical monotheism is identified as “loyalty to the principle of being and to the source and centre of all value and power” (Fowler, 1995, p.20). These distinctions indicate the value system that he proposes an individual may have if this were their expression of faith,<sup>75</sup> and also indicate how that value system is shaped.

Fowler identifies 6 age-related stages in the development of faith:

Stage 0 – "Primal or Undifferentiated" faith (birth to 2 years)

Stage 1 – "Intuitive-Projective" faith (3 – 7 years)

Stage 2 – "Mythic-Literal" faith (mostly in primary school age children)

Stage 3 – "Synthetic-Conventional" faith (arising in adolescence)

Stage 4 – "Individuative-Reflective" faith (usually mid-twenties to late thirties)

Stage 5 – "Conjunctive" faith (mid-life crisis)

Stage 6 – "Universalizing" faith,

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<sup>75</sup> This is a problematic outlook in a pluralistic world that even in religious terms has polytheistic faiths that in Fowler’s terms “lacks” what “monotheistic” faiths may have.

In Stage 0, “Primal or Undifferentiated” faith is understood through the pre-language experience of trust that is instilled by relational experience. This is marked by what Fowler calls “pre-images of God” where faith is developed through trust, courage, hope and love (Fowler, 1995, p.121). He considers that these aspects of an individual’s life start to be formed at this stage. If they are absent, this is detrimental for the future; the foundations of “faith” are being laid at this stage.

In Stage 1, "Intuitive-Projective" faith is developed through the imagination, influenced by the emotional dimension and the examples provided by others. There is “a relative fluidity of thought pattern”, for example, through fantasy. Children explore a variety of feelings and even frightening emotions, and may not as yet be inhibited by logical thought (Fowler, 1995, p.133). During this stage, faith can take them to new places in their thinking as the freedom of imagination enables them to explore stories and ideas which can instil a sense of strength or of fear. This begins to create a desire within the child to find out what is, or is not, real (Fowler, 1995, p.133).

In Stage 2 “Mythic-Literal" faith describes the faith of primary school age children. They use ‘story’ in a predominantly literal way to process the beliefs of those in the community around them (Fowler and Dell, 2004, p. 21). Stories are used to make sense of their world. The character of these stories change as the role of fantasy, predominant in Stage 1, reduces. As a result, a more linear view of life emerges which has an increasingly structured outlook. Children become more socially aware and expect to be treated fairly; seeing justice as part of their relationships (Fowler, 1995, p.149; Kay and Nye, 1996, p.18).

In Stage 3 "Synthetic-Conventional" faith emerges in adolescence as the world of the individual becomes broader to include family, school, work, street society and religion. Faith developed thus far requires adaptation to the increasing complexity of life and relationships. Fowler suggests that, for some people, this will be the last stage they will reach in faith development. Those at this stage are described as having a cluster of beliefs but as yet, not having come to the point where they are sufficiently self-aware of why they hold these beliefs and the extent to which they wish to keep them. This “ideology” (Fowler, 1995, p.173) forms part of individual identities; it is an awareness of the past and anticipation of a future.

Fowler's Stages 4, 5 and 6 (see Child Development Table in Appendix 7) go beyond the focus of this thesis. Each of these stages demonstrates the all-encompassing faith development theory Fowler devised to account for how individuals' faith can become different at different stages of life (Watts et al., 2005, p.110).

*b. Insights*

Fowler's theory shifts the primary focus of the concept of faith from religious association, to focus on trust. The Mythic-Literal stage provides an example of this. The Mythic-Literal stage is associated with school children who, according to Fowler, have a strong sense of justice and fairness. When describing children at this stage (middle childhood and beyond) he notes that:

They do not construct God in particularly personal terms, or attribute to God highly differentiated internal emotions and interpersonal sensitivities. In making sense of the larger order of things, therefore, this stage typically structures the ultimate environment – the cosmic pattern of God's rule or control of the universe – along the lines of simple fairness and moral reciprocity. God is often constructed on the model of a consistent and caring, but just ruler or parent. In this stage one often sees a sense of cosmic fairness at work: the child believes that goodness is rewarded and badness is punished (Fowler et al. in Roehlkepartain et al. (eds.), 2006, p.39).

During this stage, trust is constructed through interaction with others and there is an expectation on the part of the children that the way in which they treat others will be how they are treated themselves. Anything beyond their understanding, such as a god-figure, is understood in anthropomorphic terms.<sup>76</sup> A child at this stage constructs meaning through narrative and Fowler notes that:

In shaping meanings the mythic-literal child primarily employs narrative. In this respect, this stage provides a permanent contribution to meaning making. Stories are as close as the mythic-literal stages

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<sup>76</sup> This was evident in my first research that a hospitalised child viewed their god as an absentee parent. In other words, God was busy doing other things and will get around to give attention to them and resolving their health.

come to reflective synthesis (Fowler et al. in Roehlkepartain et al. (eds.), 2006, p.39).

This approach to the construction of meaning is related to how other children have developed their experience by listening to stories, sharing their own stories and in doing so, creating an expanding world of meaning within which they, themselves, are part of the narrative.<sup>77</sup>

### *c. Critique*

Fowler addressed criticisms as he developed his theory of faith development. One key criticism centred on his use of the term “faith.” Fowler’s approach has been considered as being consistent with religious development, leading to suggestions to associate his work more closely with this field (Fowler and Dell 2006, p.42). Others have suggested that his definition of faith is not one of universal struggle but associated with those who are committed to a religious faith community. Others describe the term “faith” as being misplaced, suggesting that if it were replaced by a term like “ego development” there would be no difference in meaning (Fowler, 1995, p.92). It is understandable that the term, “faith,” is closely associated with religious communities. While some hesitate to endorse Fowler’s use of the term due to its association with religion, there are also those within religious communities who would disagree with the general direction of Fowler’s definition of faith. Craig Dykstra objects to Fowler distinguishing the structuring and functioning of faith from the substance, content, and practices of the Christian faith (Dykstra in Dykstra and Parks (eds.), 1986, p.251). There are those, who are not religious, who are reluctant to use a term associated with religion, and there are those who are religious who believe “faith” cannot be used meaningfully out with the context of a religious community and that to do so only causes confusion.

While Fowler explains “faith” in terms of trust, the word has associations beyond its religious associations. Despite Fowler trying to define the concept in generic terms, his study draws from 359 interviews with a predominantly white population (97.8%) from a predominantly Christian or monotheistic belief system (96.4%), based in the US and Canada from 1972 to

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<sup>77</sup> This is a helpful insight for the methodology of this thesis that encourages children at this stage to create a narrative and how they can be part of that story.. It provides a promising direction with children at this stage and how they generate and work through meaning.

1981. It is questionable as to how relevant these findings are 30 to 40 years later in a European context that is secular and pluralistic, and where people's construction of meaning is no longer based on a monotheistic framework.

Although Fowler studied 25 children for Stage 2, the empirical evidence, by nature of the age of the children, is thin for Stage 0 and the data is not robust (Fowler, 1995, p.121). In total, 54 children between 0 – 12 years old were recruited; 88% of the children, 0-6 years, were identified as Stage 1 and 72.4% as Stage 2. Fowler also changed his approach amongst the children he interviewed. The interviews were usually two and half hours long but Fowler says: "Our interviews with children are briefer and do not expect as much self-aware reflection as does the adult and adolescent approach." (Fowler, 1995, p.310)

There is no indication of how the interviews were shortened, which interviews were shortened and which, if any, of the 34 questions used were omitted. It would have been helpful to know the direction of questioning and the extent to which this approach produced the best form of data to support the conclusions drawn.

Another key criticism of Fowler's approach concerns the emphasis placed on the cognitive dimension of child development.<sup>78</sup> This emphasis resulted in an ambivalent response to Fowler's faith development theory, illustrated by the acknowledgement of the editors of *The Handbook of Spiritual Development in Childhood and Adolescence* that:

Although stage theories such as Fowler's have been criticized for their strong cognitive basis and for suggesting that children are limited to less mature faith, they have been invaluable in allowing the study of the transcendent domains of religion, spirituality, and faith to gain more serious consideration" (Roehlkepartain et al. (eds.), 2006, p.7).

Fowler's thorough and accessible research has dictated the direction of much of the discussion in the field of faith development theory, leading to a focus on the study of the

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<sup>78</sup> What is unusual about this criticism is that this is what Fowler accuses Piaget of.

cognitive dimension of children. Further research (of which this thesis is a part) is emerging and additional options are being considered to complement Fowler's work, and in order to reflect the multiple dimensions of the child.

A final key criticism of Fowler's Stage approach is that it does not hold as rigidly to the structure he proposes as do the theories of Piaget and Erikson. Erikson and Fowler differ as to how stages progress. Erikson suggests a progression through the stages, but with development into further stages potentially hampered by the extent to which the previous stage has been achieved. He suggests that some children may have an accelerated developmental experience of faith which places their faith ahead of the anticipated stage but that these incidences are peripheral to the general pattern.<sup>79</sup> Erikson implies a more evolutionary development than Fowler, where each stage is dependent on the previous one and integrated to the next; whereas Fowler implies a looser connection between development and the progression through the stages of faith. If an individual is found to depart from the development documented in Fowler's stages, then their faith journey may not be adequately described by his theory. For Erikson, development in one stage is influenced by the difficulties encountered at a previous stage, whilst Fowler makes no such suggestion. As such, although Erikson has been accused of being descriptive in his theory, he demonstrates a greater cohesion between the stages than Fowler does.

Fowler acknowledges that the strength of his faith development theory is in matching the competences of the child with the formation of meaning in a child's life. This can be seen clearly in religious formation within an educational setting. He states that:

The stage theory makes its contribution, however, by helping to match the competences of each stage – and the operations of mind and emotion that characterize them – with ways of teaching and with the symbols, practices, and contents of faith at different levels of reflective inquiry and complexity (Fowler et al., 2006, p.43).

The staged approaches of Fowler, Erikson and Piaget may help an educationalist understand the competences of a child, however, the change in context and experience for a child in a

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<sup>79</sup> This has been modified by Streib to give more consideration to religious style. This results in a more continuous process and accounts for regression (2001, p.154)

healthcare setting may present a different perspective that these longitudinal theories cannot adequately explain. The focus of spirituality in an acute paediatric setting is on the individual's health at a specific point in time, rather than on their long-term educational development. As such, if used in isolation, Fowler's Faith Development Theory may restrict understanding of the spiritual needs of a child and the proposed spiritual care responses may be inadequate or irrelevant (Pehler, 1997; Steen and Anderson, 1995; Davies, Brenner, Orloff, Sumner, and Worden, 2002; Fosarelli, 2003, p.85; Ford, 2007).

As with Piaget's theory, Fowler's theory can be reduced to a technique that can become restrictive in application. This is illustrated by American nurses Hart and Schneider's (1997) adoption of an assessment tool, devised using Fowler's developmental framework in order to recommend appropriate interventions. Hart and Schneider offer proposals for religious spiritual care and published in a Christian nursing journal to emphasise their point (Hart and Schneider; 1997, p.267).<sup>80</sup> In doing so they make spiritual care synonymous with religious care. They aim to be therapeutic by advocating religious goals which would have limited general application and be potentially damaging to a patient's spiritual health. This demonstrates the danger of using one specific psychological theory in practice when it is considered that it can comprehensively address the concept of spirituality. Pehler, despite holding views in line with the developmental approach of child psychology, admits that studies carried out in the early 1990s tended to focus on religious clues and cues, and that more exploration into "the spiritual response children may have to a life changing event" would reduce the danger of applying inadequate theories that might result in paternalistic practices (Pehler, 1997, p.57). However, the potential problem with this prescriptive approach is that healthcare professionals may become preoccupied with identifying stages of childhood spirituality; they may be less aware of the processes or experiences of what Fowler calls "faith" and fail to identify experiences that move a child from one developmental stage to the next (Parks 1986, p.139). Attention would be given to the *structuring* of spirituality rather than the *substance* of spirituality. This thesis is concerned with the content and the construction of spirituality through identifiable developmental building blocks and not what it *should* look like at a certain stage.

Parks' concern is that Fowler places strong emphasis on transcendence as a feature of his faith development theory, and gives inadequate attention to immanence (Parks in Dykstra and

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<sup>80</sup> This is not an isolated incident (Ames and Klousterhouse, 2002, p.74).

Parks (eds.), 1986, p.139). Fowler suggests that just as a moth is attracted to light, so humanity is attracted to something transcendent; individuals should aspire to the value and power of an ultimate reality. A longitudinal approach where enlightened faith is developed through stages does lose relevance for those whose life is shorter. Children may not view “faith” in terms of their whole lifespan, but see it more in the immediacy of their present context. If Parks’ concern is justifiable, then Fowler’s theory is not universally applicable in its current form.

#### *d. Application*

A healthcare professional may be able to discern the way in which a child interprets their health in terms of trust, if they are able to accurately identify a child who is at the mythic-literal stage. The trust developed would be based on the child’s experiences and stories would develop through, for example, their parents and the staff with whom they have built a rapport. In line with the description of a child’s *modus operandi* at this stage of development, trust would be broken or questioned if a story became inconsistent with their experience. They would question whether they had done something wrong, or would lose trust in those from whom they had heard the stories. As such, Fowler’s description would be hard to apply if a child’s framing of meaning does not relate to a transcendent being.

The concept of reward and punishment, which Fowler describes in relation to the mythic-literal stage, becomes irrelevant if a child does not believe in God. This became apparent in my previous research into the spiritual needs of hospitalized children with complex healthcare needs (Bull, 2007). Children did not introduce God into discussions until prompted by the researcher, and then framed their perspective of God in terms of the role model of an absentee parent but with no mention of reward or punishment. Fowler’s construction of meaning is quite specific in its conceptual language and this limits its use. To overcome this limitation we must find another construct with the capacity to include transcendence, but framed in terms more applicable to those who cannot explicitly refer to transcendence to build their sense of meaning.

Fowler makes a valued comparison between polytheism, henotheism and monotheism, and identifies the pull of the focus points in a person’s life. When applied to the new definition of spirituality, Fowler’s theory provides a building block that shows the tensions children may experience as they develop trust through relationships and seek justice in their experience,

while recounting life stories. In assessing a child Fowler establishes what these focal points are, and the extent to which the pull to them is being disrupted. Developed further in relation to the stages of Fowler's theory, the nature of this focus can affect the affinity a child has with attaining that ultimate concern.

Few researchers in the field of spiritual care have drawn together a collection of building blocks from existing theory in the way combined in this study. I will argue that insufficient attention is given to the immediate environmental context for a child's development in relation to spirituality. Journal publications by healthcare professionals on childhood spirituality tend to focus on developmental theory which gives consideration to the qualities of the child, rather than focusing on what spirituality might mean for a child in a given context. Others, in fields such as Christian education, have also noted this tendency (Estep and Breckenridge in Ratcliff (ed.), 2005, p.324). To redress this, attention must be given to the ecological dimension of a child's world to draw insights from the child in context. This does not constitute a substitution of one psychological theory for another, but rather a broadening of the understanding of the multi-dimensional nature of a child's development.

Combining the theories of Piaget, Erikson and Fowler provides insight into how a child thinks, socially develops, and constructs "faith". However, insights from these theories need to be contextualised in an environmental setting that enables them to be related specifically to children in hospital; and attention must be given to the environmental dimension of a child's life and how it contributes to their construction of meaning. The next section examines the work of the psychologist, Urie Bronfenbrenner, who has extensively explored the ecology of the child. His theory introduces the final building block to facilitate the redefinition of childhood spirituality.

#### *4. Urie Bronfenbrenner*

##### *a. Outline*

The study of the ecological perspective of the child emerged late in the field of developmental psychology, when Urie Bronfenbrenner published *The Ecology of Human Development* in 1979. From 2000 he developed his social psychological Bioecological Theory by including consideration of the biological influences on human development. Bronfenbrenner's definition of the ecology of human development is that it:

involves the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded (Bronfenbrenner, 1979, p.21).

The focus of the theory is on individuals in a context. It enables examination of how that context is understood by the individual through the connections made with the context and the individuals within it, and the connections made between the systems themselves which make up the individual's context. These contexts comprise of five systems. Firstly, the microsystem<sup>81</sup> which incorporates an individual's biology,<sup>82</sup> home, school and peer group. Secondly, mesosystems,<sup>83</sup> comprise contexts such as school,<sup>84</sup> peers, family, the playground, healthcare services and religious institutions. Thirdly, exosystems<sup>85</sup> are the contexts of which the child has no experience, but which have an indirect influence on them, for instance their parent's work context, friends of family, mass media, neighbours, legal services and social welfare services. Fourthly, macrosystems,<sup>86</sup> contain the overarching characteristics of any culture, subculture, or broader social context.<sup>87</sup> Bronfenbrenner later added the chronosystem, which refers to the evolution over time of the external systems, including socio-historical conditions. There is an inter-relationship between the systems that makes a connection between them (Tudge, Mokrova, Hatfield, and Karnik., 2009, p.201; Bronfenbrenner<sup>88</sup> in Wozniak and Fischer (Eds.), 1993, p.25).

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<sup>81</sup> "A microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics." (Bronfenbrenner, 1979, p.22)

<sup>82</sup> The biology of the child was a later environmental addition in the Bronfenbrenner's Bio-Ecological Theory.

<sup>83</sup> "A mesosystem comprises the interrelations among two or more settings in which the developing person actively participates (such as, for a child, the relations among home school, and neighbourhood peer group; for an adult, among family, work, and social life." (Bronfenbrenner, 1979,p.25 )

<sup>84</sup> The reason why the school appears twice is that it qualifies for each of the systems because of the nature of that context. So there is a physical dimension to this context but also the relations that a child can have within the school.

<sup>85</sup> "An exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person." (Bronfenbrenner, 1979,p.25 )

<sup>86</sup> "The macrosystem refers to consistencies, in the form and content of lower-order systems (micro-, meso-, and exo-) that exist, or could exist, at the level of subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies." (Bronfenbrenner, 1979,p.26)

<sup>87</sup> For example, a child's sense of meaning and connectedness can be affected by a culture of belief system that they are already a part of. This might be complicated when their culture encounters the culture of the healthcare system that might have different values from the family, and so the clash of these systems may give concern to the child as they try to make sense of the changing world around them.

<sup>88</sup> The article is entitled, "The ecology of cognitive development: Research models and fugitive findings" (pp.3-46)

The five systems are often represented pictorially as a target with the microsystem at the centre surrounded by a number of increasing-sized circles and the largest circle, representing the chronosystem, at the outside. According to Bronfenbrenner, children develop an awareness of these circles through established dyadic links with their surroundings. These systems are acquired and understood through the wide range of connections children make. Bronfenbrenner states that:

As the child's phenomenological field expands to include ever wider and more differentiated aspects of the ecological environment, she becomes capable not only of participating actively in that environment but also of modifying and adding to its existing structure and content (Bronfenbrenner, 1979, p.47).

Bronfenbrenner explains how the child is connected with these systems, calling one such connection "molar activity"<sup>89</sup> due to a pattern of behaviour which is more than an action, by virtue of the underlying momentum it represents (Bronfenbrenner, 1979, p.45). As such there is intent in the ongoing nature of the action. The molar activities of "invocation" and "interaction" are a manifestation, and may in themselves constitute a means to create meaning by connecting to other environments where an individual's settled sense of meaning is more accessible. Such activity "makes for persistence through time and resistance through interruption until the activity is completed" (Bronfenbrenner, 1979, p.46).

Another means for the child to connect with the systems that make up their context is through other individuals. Bronfenbrenner's ecological theory refers to this means of connection as a "dyad".<sup>90</sup> This dyad could be the child's parents and the activities they do together in the community. Bronfenbrenner underlines the importance of a dyad when he says that "the dyad is the most versatile building block of ecological structure" (Bronfenbrenner, 1979, p.218). Bronfenbrenner is interested in the dyad in relation to the nurturing element of a child's development.

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<sup>89</sup> "A molar activity is an ongoing behaviour possessing a momentum of its own and perceived as having meaning or intent by the participants in the setting." (Bronfenbrenner, 1979,p.45)

<sup>90</sup> "a dyad is formed whenever two persons pay attention to or participate in one another's activities." (Bronfenbrenner, 1979,p.56)

The combination of a dyad and a molar activity is what Bronfenbrenner calls a “joint activity dyad” and occurs when a child, and a person who is very close to the child, are involved in an activity which is significant and connected with the child’s ecological system. For example, a parent present in the child’s microsystem would be identified as a “primary dyad” and could also be a “supplementary link” involved in the child’s mesosystem (Bronfenbrenner, 1979, p.210). This is reflected in one of Bronfenbrenner’s hypotheses<sup>91</sup> when he states that:

The developmental potential of settings in a mesosystem is enhanced if the roles, activities and dyads in which the linking person engages in the two settings encourage the growth of mutual trust, positive orientation, goal consensus between settings and an evolving balance of power responsive to action on behalf of the developing person. A supplementary link that meets these conditions is referred to as a *supportive link* (Bronfenbrenner, 1979, p.214).

The influence of the relationship between the child and the linking person may still be felt, even when that person is not present in the child’s microsystem. The child appreciates the mesosystem more because the linking person (often the parent) is able to relay stories and information to the child:

The developmental potential of a setting in a mesosystem is enhanced if the person’s initial transition into that setting is not made alone, that is, if he enters the new setting in the company of one or more persons with whom he has participated in prior settings (Bronfenbrenner, 1979, p.211).

Bronfenbrenner is noted for developing and changing his theory, notably his later inclusion of biology as part of a person’s microsystem. He also introduced the chronosystem, which introduced the concept of time into his contextual framework. Developing changes to his theory were evident in his Bio-Ecological Systems Theory and his Process Person Context Time Model (PPCT)<sup>92</sup> (Tudge et al., 2009, p.199). The Process Person Context Time Model

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<sup>91</sup> In Bronfenbrenner’s book, *The Ecology of Human Development: Experiments by Nature and Design*. He has a series of hypotheses that he develops through the whole book. This is Hypothesis 34.

<sup>92</sup> It is important to note that both this theory and model have developed over the years as Bronfenbrenner has made revisions. Therefore it is important to note what aspects and what part of the historical development of this theory that this thesis draws upon (Tudge, et al, 2009, p.199) This thesis draws from what Tudge et al calls the “mature” theory, which was the latest in Bronfenbrenner’s theory. It does not utilise all aspects but applies what is appropriate to this development of this thesis.

(PPCT) is “an operational research design” which enables Bronfenbrenner’s theory to be researched (Tudge et al., 2009, p.199).

In this model, Bronfenbrenner used the term “*proximal processes*”. He states that:

[H]uman development takes place through processes of progressively more complex reciprocal interaction between an active, evolving bio-psychological human organism and the persons, objects, and symbols in its immediate external environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time. Such enduring forms of interaction in the immediate environment are referred to as *proximal processes* (Bronfenbrenner and Morris, 1998, p. 996, emphasis in original).

These proximal processes are the established means of connection that children use to make meaning in their contexts; as they change biologically these proximal processes must reflect that development (McPherson, 2004, p.224). A proximal process must be a repeated event or one that is consistent with how a child chooses to connect (Bronfenbrenner and Ceci, 1994, p.572). Otherwise, the child may lose touch with a context that made meaning in the past (Bronfenbrenner and Evans 2000, p.118).

Bronfenbrenner introduces three types of “personal characteristics” which come into play in a given context; “demand”, “resource” and “force”. Demand (formerly *personal stimulus*) refers to age, skin colour, gender and physical appearance (Tudge et al., 2009, p.200). Resource relates to “mental and emotional resources such as past experiences, skills and intelligence, and social and material resources (access to good food, housing, caring parent, and educational opportunities)” (Tudge et al., 2009, p.200). “Force” characteristics are defined as “differences of temperament, motivation, persistence” (Tudge et al., 2009, p.200). In relation to “force”, Bronfenbrenner acknowledges that while children may be affected by context, they can also be an influence for change within that context. The character of this dual dynamic is determined by ‘bi-directional influences’ which occur at different levels; whether it is a person’s presence in a context, and how they respond by the use of their resources; or whether they take active measure to change the context. This breakdown of

levels enables further insight into how a child makes meaning by using “force.”<sup>93</sup> If, for example, the working environment of a parent means that the parent relates to the child in an irritable fashion, this may cause stress and affect the child’s environment. The child, in turn, may respond in a way that counters this; perhaps by rebelling, or being emotionally upset or withdrawn. Understanding this could encourage the parent to make different working arrangements that better accommodate the needs of the child.

*b. Insights*

Bronfenbrenner’s theory identifies the ecological system of the child; an important feature of child development which does not appear in other developmental theories. His approach has a very different emphasis from that of the stage theories of Piaget and Erikson. Rather than focusing on development over a period of time and marking identifiable stages, it is concerned with the immediate context within which the person is located; the current content of a person’s life as they see it, use it and connect with it. Additionally, his theory emerged at a time when laboratory-based theories were predominant. Bronfenbrenner moved away from this approach, seeking to gather data in the small and large settings of children in a way similar to that seen in this study.

Bronfenbrenner highlights the shift in approach, stating that:

Perhaps the most unorthodox feature of the proposed theory is its conception of development. Here the emphasis is not on the traditional psychological processes of perception, motivation, thinking and learning, but on their content – what is perceived, desired, feared, thought about, or acquired as knowledge, and how the nature of this psychological material changes as a function of a person’s exposure to and interaction with the environment. Development is defined as the person’s evolving conception of the ecological environment, and his relation to it, as well as the person’s growing capacity to discover, sustain, or alter its properties (Bronfenbrenner, 1979, p.9).

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<sup>93</sup> The term “force” is also used by Fowler. He uses it in relation to a person having a life force where they engage with making meaning of their world.

Bronfenbrenner's theory is characterised by a more systemic approach; not having the linear style of stage theories. The implications of this are described by Estep et al. who note that:

Systems thinking represents a fundamental change from focusing on the content of knowledge and instruction to a consideration of pattern, process and communication as the essential components for explanation and description (Estep et al. 2005, p.327).

Instead of looking at how a person acquires more knowledge to achieve a higher task, Bronfenbrenner's focus is on the individual in context and how they relate and connect with other contexts. It is the appreciation of how an individual understands their immediate context; how connections can be made between the five systems; and what meaning the individual invests in such connections, which can help a healthcare professional understand their immediate context. In addressing this Bronfenbrenner notes that:

Activities differ in the extent to which they invoke objects, people, and events not actually present in the immediate setting. Such invocation may be accomplished through conversation, storytelling, fantasy, pictorial representation, or a variety of other media (Bronfenbrenner, 1979, p.47).

Bronfenbrenner's theory identifies the flow of influence taking place between the child and the environment; and identifies what factors contribute to this through the connections the child makes and is provided with. Rather than focusing on the achievements and failures of the child towards becoming a pre-defined "mature" person, the value is placed on the environmental dimension. Concern focuses on the nurture of the child and focuses on optimising environments. The responsibility rests on those whom the child encounters within the five systems to provide an environment that nurtures the child<sup>94</sup>.

Using this approach, children are not diminished to being passive elements dominated by the environment, but are instead active agents who engage with their environment; interpreting what that environment means to them. Bronfenbrenner also acknowledges bi-directional

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<sup>94</sup> The resting of responsibility to provide a context is an emphasis that is an important characteristic for a SAT, where the SAT is discovering its responsibilities of what the child's spiritual needs might be.

influences of the individual on the environment and vice versa; leading to a measure of uncertainty as to the extent to which a change in the child's setting disrupts how they perceive, and relate, to it. This measure of uncertainty accounts for Bronfenbrenner's continuance to develop an approach to understanding the person's biology as context.

### *c. Critique*

Bronfenbrenner continued to develop his theory until his death in 2005; the most significant shift being its development to a Bio-Ecological Theory. This revision dealt with two criticisms; firstly, that he had insufficiently addressed the role of the person within the context; and secondly that he had not addressed the place of "time" in the development of a child. He addressed these criticisms by integrating the biology of the individual in the microsystem and by adding the chronosystem to accommodate the place of time in the context of an individual. Bronfenbrenner gives little consideration to the step-by-step development found in stage theories. It is important to understand Bronfenbrenner's focus on a child's ecological system when comparing his theory with Erikson's explanation of the internal interactions taking place. Erikson compares individuals through the stages of their social developmental lifespan, whilst Bronfenbrenner describes the dimensions of an individual's internal interactions as part of a microsystem and then defines them through how they are integrated into the other systems they relate to at that time. Bronfenbrenner's approach allows us to understand the individual in relation to their immediate context, whereas Erikson's theory is both projective and retrospective. He draws from a perceived reality of the future and compares that to a rather deterministic past.

It could be argued that Bronfenbrenner's theory is too general to take sufficient account of the complexity of a child. Social psychology focuses on small groups and interpersonal relations in exploring how children make meaning in different environments (such as the school classroom) that they connect to. When applied to other settings, further research would be required to understand the impact that different social settings, such as hospitals, may have upon a child. This thesis seeks to add to that research through an exploration of the social interaction between a child and an adult, such as a parent, in attempting to reconstruct a concept of childhood spirituality in the context of a healthcare setting. The benefit of Bronfenbrenner's theory in developing the building blocks of that concept is in the focus he places on the nurturing dimension.

#### *d. Application*

Bronfenbrenner's theory importantly considers the continuing impact of the environments which although a child is absent from, may still have a significant influence on the child's life. Even though there is a loss of physical connection, the family home has been an accessible environment for the child. This can be achieved by the supportive dyadic links such as parents and family resources, whether the child is from a poor or affluent background.<sup>95</sup> The scenarios studied in this project will benefit from psychological perspectives which understand the development of a child using the stage theory of Piaget, Erikson and Fowler, and Bronfenbrenner's systemic ecological theory.

Bronfenbrenner's theory allows for the consideration of a child's perspective of an environment or scenario as they recall it, such as their view of the home environment whilst in hospital. This approach has the capacity to uncover the connections the child makes as a result of parents and friends visiting, phone calls, or remembered experiences of home. It offers a means to interpret children's narratives and how they perceive environments other than the hospital. Children's absence from home or school can affect how they narrate, or frame, their lives to deal with the environment they are currently in.

I will draw from Bronfenbrenner's theory to develop a framework for understanding how children in hospital acquire and use meaning, in order to formulate a new conceptual framework to understand children's awareness of their surroundings. Estep et al. explored Bronfenbrenner's ecological theory in terms of spirituality and locate the generating of meaning at the interaction between the individual and the context they are within. They note that:

Spirituality from an ecological perspective involves the mutual accommodation between an active, growing child and the changing properties of the immediate setting in which the developing child lives, as this process is affected by relations between those settings and by the larger contexts in which these settings are embedded (Estep et al. 2005, p. 332).

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<sup>95</sup> What also requires consideration is that such dyadic links could be harmful and identifying them is just as important, (Bush, and Pargament, 1995, p.260; Butter and Pargament, 2003, p.179)

“Mutual accommodation” can be seen as an interactive process of an active awareness created by a child. Hospitalised children have to work out what their new surroundings mean to them as they are in a context where the usual construction of their life routine has been disconnected. Bronfenbrenner’s Bio-Ecological Theory adds significantly to the understanding of the idea of mutual accommodation in several ways.

Firstly, the theory aids understanding of the implications of contextual dimensions on children’s sense of how they might familiarise themselves with their surroundings. It considers the different environmental settings where children formulate their understanding of what a new setting means to them, and shows how this can be disrupted by changes of environment. The inclusion of biology in Bronfenbrenner’s Ecological Theory is a significant factor. The children studied in this project live in the context of unhealthy bodies which may leave them disconnected from their physical existence and this can affect how they relate to other environments. Lying at the heart of Bronfenbrenner’s theory is the ecological aspect of the “person-context interrelatedness” (Tudge et al., 2009, p.199). The person’s body can in itself create a spectrum of biological context for a child who has a chronic condition, such as cystic fibrosis or a sudden debilitating virus or a traumatic event, such as a broken limb or a life-threatening illness (Sourkes, 2007, p.40). Disconnection existing within the body may be compounded by children being removed from their usual settings, longing to be home, or wishing to be in contact with friends at school. As such, Bronfenbrenner’s theory provides a useful framework to explore the breadth of a child’s present environment, both immediate and distant.

Another significant feature of Bronfenbrenner’s theory that is relevant to this research is the inclusion in the microsystem of the “experience” of “physical conditions and events” (Bronfenbrenner, 1979, p.22). Children coming into hospital physically experience a setting which is usually considered as part of their exosystem, which then becomes part of their microsystem. The level of tension between these systems that the child experiences could be affected in part by the duration of their stay and the connection their parents make by being present.<sup>96</sup> These factors can impact on their understanding of home, in terms of it being an environment associated with an exosystem. For instance, as children experience protracted hospital stays, there is a possibility that the perception of home shifts from an immediate

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<sup>96</sup> The child can also be indirectly affected by the level of support a parent receives from a healthcare professional and how that supports the parental role for the sick child, (Robinson, Thiel, Backus and Meyer, 2006, e727)

context to a distant one. The hospital environment has an increasing sense of permanence as their hospital room becomes their perceived microsystem<sup>97</sup>. If the hospitalized child has a chronic condition that has required repeated hospital visits, the hospital may become categorized not only as a mesosystem, but also as a microsystem. The child has incorporated this environment into their physical world even when absent from it and admissions would no longer constitute a dislocation for the child, who would be able to move, without experiencing disruption, from one system to the other. However, for a child who experiences a trauma resulting in a sudden admission to a hospital they had no prior experience of, the hospital would remain part of an exosystem even if the child had gleaned some knowledge of a hospital environment from friends or TV.

This movement between systems, between hospital and home, is what Bronfenbrenner refers to as an “ecological transition”<sup>98</sup> (Bronfenbrenner, 1979, p.26). He asserts that, “every ecological transition is both a consequence and an instigator of developmental processes” (Bronfenbrenner, 1979, p.27). If this is the case, moves in and out of hospital could accelerate some aspects of development, whilst slowing down others. Although this thesis is not primarily concerned with the development of spirituality, consideration should be given to the effect of movement between systems upon the development of spirituality. Movement between systems increases the complexity of a child’s settled perception of their surroundings and the process of establishing their meaning-making process. Using Bronfenbrenner’s approach, the healthcare journey is interpreted as “developmental phenomena” (Bronfenbrenner, 1979, p.27).<sup>99</sup> This journey generates a spiritual need best understood with reference to Bronfenbrenner’s theory, which can assist our understanding of how children relate their spirituality to the new environment, while drawing from absent environments to give meaning that works in their current setting. If there is a difference between environments, this can lead to a developmental experience. Including this perspective in the framework to understand childhood spirituality helps to describe how a child makes new connections of meaning through this developmental experience, if the complexity of a child’s awareness has grown, and if their admission to hospital has involved new meaning-making.

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<sup>97</sup> In therapeutic terms the responsibility of parents and professionals is to deconstruct this as this sense of permanence could result in a child’s loss of motivation and hope of return home.

<sup>98</sup> “An ecological transition occurs whenever a person’s position in the ecological environment is altered as the result of a change in role, setting or both.” (Bronfenbrenner, 1979,p.26)

<sup>99</sup> “Human development is the process through which the growing person acquires a more extended differentiated and valid conception of the ecological environment, and becomes motivated and able to engage in activities that reveal the properties of, sustain, or restructure that environment at levels of similar or greater complexity in form and content.” (Bronfenbrenner, 1979, p.27)

There is a possibility that if there are no nurturing links in place, the child may experience a loss of spirituality as connections are not made.

In this study, children encounter for certain periods of their life two cultures, hospital and home, and these cultural settings may differ significantly. Bronfenbrenner describes children who have grown up in two cultural contexts as “transcontextual” persons. The meeting of these two settings in the mind of the child might result in a clash between them. For example, a child may not want to go into hospital as a result of being aware of the potential disconnectedness they will experience as a result. Their feeling of security may depend on certain meaningful connections and links, and if these are disturbed by a change in context, the child may have to construct a new sense of meaning (Pargament, Smith, .Koenig, and Perez, 1998, p.721; Pargament, Zinnbauer, Scott, Butter, Zerowin and Stanik, 1998, p.86).

Bronfenbrenner’s theory assists the healthcare professional to appreciate the disconnectedness that hospitalised children might experience when home, their usual microsystem, becomes an exosystem; and hospital, usually an exosystem, becomes their new microsystem. Bronfenbrenner stipulates two connections that link these two systems. Firstly, events which happen in the exosystem affect the microsystem. So, missing a family event at home could accentuate the child’s sense of disconnectedness and parents and staff may need to compensate for this. Secondly, a person’s experience in the microsystem has an impact on the exosystem. So, disruption in the exosystem caused by a child’s poor health could have an impact upon the child. While that influence may be on the child, the child can also project into the exosystem so that the routine of the home becomes centred on the child’s microsystem. The parent might be completely absent from the exosystem, missing work or unable to attend to other siblings. Tension is created between the two settings as parents create a new microsystem by trying to make links with an exosystem so that it has the features of a microsystem. The action of the parents brings back the need for them to be a “supportive link”; generating activities that focus on the previous order of settings where the home was the child’s microsystem and the hospital the exosystem.

The child’s awareness of tension between the hospital and home settings may vary according to developmental stage and how they connect with their surroundings. Tension may be resolved by a child being provided with a day pass or school pass. The school, or home, then become a mesosystem as the child is involved in both. For a sick child some aspects of the

“immediate external environment” will have changed, affecting the interaction that the child is familiar with. Useful observations might be made as to how a child interprets change in these proximal processes, and what language is used by, or around, the child that affects disruption to the physical and biological environments of the child. It is highly likely that such a multiple change in environment would mean that a child admitted to hospital would experience a distressing sense of disconnectedness.

Bronfenbrenner assumes that human development does not work in a vacuum and similarly we can assume that neither does spirituality. If we are to understand the primary emphasis of a new construct of childhood spirituality, then we must acknowledge that it emerges out of, and shapes, the interaction between an individual and their context. When there is a bi-directional influence, the context also shapes the individual through the meaning they draw from their environment; whether that is through people as a dyadic link, activity as a molar activity or a child’s own resources. Considered through Bronfenbrenner’s theory, the connections children make will be shaped by their internal interactions together with the connections they have or make with the five systems.

Bronfenbrenner’s theory provides an infrastructure for appreciating how children relate to their contexts through what he calls the “ecology of mental life” or a “mental mesosystem” (Bronfenbrenner, 1979, p.47). He suggests that children have a mental construction of how they perceive their surrounding contexts, and a mental construction of how they draw and make meaning of their connections with that environment. For example, a hospitalised child’s imaginings of home discussed with a parent might create a picture of meaning that the child can connect to. This picture can then feed back into the child’s present context to engender a sustaining force. This would suggest that a child’s narration of their mental mesosystem can be identified through assessment, raising awareness of the support a healthcare team can provide.

Parents can play a significant role in developing their child’s meaning-making in relation to new experiences such as a hospital stay, especially if they have performed this role in other settings such as when leaving the child at nursery. If the parent has explained what might happen in hospital, this can increase a child’s ability to process meaning and to develop a better sense of perceived, or co-constructed, imaginary surroundings. The existence and level

of significance of this link might reduce a child's distress over repeated visits to hospital.<sup>100</sup> This dyadic function could also be carried out by a member of the healthcare team by, for example, explaining a procedure before starting a clinical intervention. The explanation of the procedure may serve as a link to an unknown setting where the child is trying to understand the context. Bronfenbrenner suggests that an individual who serves as a link between two settings will show varying levels of support for the child, depending on the type of link they have had with that child previously. A child's confidence in a parent may be strong, compared to confidence they have in a more distant relative taking the parent's place. Continuity of parental involvement enables the child to carry experience from other settings, and transfer links made in previous settings; applying them to the new situation.

The dyadic function can be carried out by an individual in the context of the new setting, and a dyad could be a child's doctor who may have influence on the child as a result of involvement in treating their illness. Bronfenbrenner believes these dyadic links between systems are crucial to the development of the child; if there is a breakdown in a relationship with a person who is part of a primary dyad, it would be harmful to the development of the child. In a healthcare setting, such a breakdown could be detrimental to the nurture of a child who has a diminished sense of connections between these systems while in hospital. Children's awareness of these links provides an indication of the level of complexity from which they may construct meaning and are able to project their perceived setting outside of a microsystem (Baker-Ward, Gordon, Ornstein, Larus and Clubb, 1993, p.1532).

A hospitalised child might perceive recovery as a molar activity. A child may play a game to cope with the boredom of hospital on realising that the hospital stay will be long; recognising that games help to pass the time and possibly overcome negative feelings. Hospitalised children have particular expectations about their home environment that enable them to cope in their immediate environment. Bronfenbrenner puts the momentum of the child's expectations down to the intent of the individual, which is, at times, not always apparent to the individual themselves. The microsystem, such as the healthcare journey of an individual, may cause molar activity which creates the connection with another system that the current microsystem is not supplying. If this is not supported, the environment may have an adverse impact on the child.

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<sup>100</sup> The work of Schneider and Mannell expand the type of support a parent can bring in terms of their own spirituality (2006, p.19)

These connections can vary. For example, the close proximity of home to hospital may allow better social resources, such as visits from friends or parents. Such resources may reduce the impact of adjustment a child might otherwise experience. For those who do not have access to these resources, the hospital can provide play areas, televisions, entertainment systems and accessible visiting patterns to enable the child to interpret a sense of meaning that relates to the displaced settings, such as home, in a better and more positive way. Bronfenbrenner's idea of "resource" offers a helpful way to understand how different children respond in different ways to similar contexts. This understanding can assist the healthcare professional in isolating the factors that contribute to a child's level of awareness in relation to the systems that make up their environment.

The insight gained from Bronfenbrenner's theory provides another building block to assist in redefining the nature of children's spirituality, particularly in a hospital environment. Bronfenbrenner's theory is useful in helping to account for children's awareness of their environment, and in demonstrating how this awareness enables them to construct and sustain a sense of meaning. It allows for the identification of the type of connections children make to other contexts while they are in hospital, and the absence or presence of molar activities and dyads serves as an immediate indicator of a child's spiritual stability. Bronfenbrenner's theory is sufficiently developed to accommodate other complexities which can be affected by the "type" of child, as differences in reaction can occur with different children even though the context may be the same.

### **C. Overall application of this chapter**

It is imperative that we describe the phenomena of spirituality and spiritual response in children before we can attempt to intervene (Pehler, 1997, p.56).

The analysis of child development theory indicates the complexity of different factors involved in children's development and highlights how children relate to others at different stages of development. In doing so it has identified the building blocks needed to create a clear conceptual framework of childhood spirituality which is consistent with the professional context of the healthcare setting, and which offers the potential for a clear assessment of what

can be known of a child's spirituality. This concept must address a child's accessibility, the manner of their connections and identify how they choose to describe their sense of meaning.

The contribution of Erikson to the development of this new concept is specific and significant; offering another dimension to understand how children at particular stages of development use their social balance to contribute to their sense of meaning in life. Similarly, in shifting from Fowler's religious narrative to an inclusive language that accounts for religion, but is not framed by it, Erickson's theory contributes to developing a concept that can relate to the professional and clinical setting of a healthcare context.

Bronfenbrenner's Bio-Ecological Theory adds another dimension to consider, as it offers an understanding of the child's comprehensive environmental framework. It provides insight into how a child connects with environments and how a change of environment may affect this connection. It establishes what measures children may take to readdress their sense of what gives meaning within that environment.

This multidimensional approach has the capacity to value the child as an entire identity (Kenny, 1999b, p.23) and enable healthcare professionals to appreciate the complexities of a child's world. A clearer and more comprehensive conceptual understanding that takes these complexities into account would constitute a positive step towards a relevant way of addressing children in an age-appropriate, contextually sensitive manner.

Child developmental psychology has assisted in establishing the foundational and core elements which need to be explored when using a Spiritual Assessment Tool (SAT); identifying the building blocks of a child's spirituality which can be seen through Piaget's "cognitive style", Bronfenbrenner's "dyadic" connections, Erikson's manner of social interaction, and Fowler's focus of meaning. In terms of Piaget's cognitive style, the awareness of how children of different developmental stages perceive their surroundings is crucial in comprehending children's expression of their reality. Bronfenbrenner's approach introduces a crucial link between understanding childhood spirituality and how to relate to a child. While the focus of this chapter is the development of an appropriate conceptual framework, Bronfenbrenner's work identifies, in broad terms, the appropriate attributes for using a SAT. The healthcare professional must have qualities which are "dyadic"; the process needs to be consistent with a child's molar activity and through these, the foundation is laid

for what Bronfenbrenner refers to as “proximal processes”. The combination of child development theories provides the breadth of insight to explore how a child constructs meaning relating both to stage and environment. The design and conducting of a SAT requires engagement at all these levels. The SAT cannot be conducted in isolation from any of the connections a child uses to remain connected.

In order to enter into the microsystem of a child, there must be a shared activity to help the child connect with absent environments. This may be achieved through the content<sup>101</sup> of the SAT, and also through the manner in which it is conducted. The design and delivery of the SAT must be consistent with the child’s momentum and intent. In Bronfenbrenner’s terms, a child will have little incentive to take part in a SAT if it does not relate closely to the child’s molar activity. The activity of a SAT, in these terms of reference, is a joint activity dyad because it involves the child and the assessor in a shared activity which has an overlapping purpose (Bronfenbrenner, 1979, p.57). This shared activity is not necessarily a balanced activity, as one individual may have greater influence than the other. In terms of the child’s environment, the SAT assessment should identify the child’s main relations in his microsystem.

Tudge et al. from their reading of Bronfenbrenner’s work, state that:

The examples that he provided (“playing with a young child; child-child activities; group or solitary play, reading, learning new skills” and so on) are the types of things that regularly go on in the lives of developing individuals. They constitute the engines of development because it is by engaging in these activities and interactions that individuals come to make sense of their world and understand their place in it, and both play their part in changing the prevailing order while fitting into the existing one (Tudge et al., 2009, p.200).

This connection between play and children making sense of their world, underlines the type of approach required to provide an environment where a child feels more able to share. This underlines the significance that play and storytelling have in the spirituality of children as

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<sup>101</sup> The selection of pictures in a card game can represent many aspects of the series of systems that Bronfenbrenner proposes.

they discover, reinvent and reinforce meaning-making in their lives (Fulton and Moore, 1995, pp.228-229; Carroll, 2002, p.185). This must be an essential ingredient of a SAT.

In order to grasp the detail of what Bronfenbrenner has identified, and to see how these building blocks relate to play and story-telling, in the next chapter I will continue to explore child development theory with particular reference to Vygotski's Cultural Historical Theory and Barbara Myer's application of Ritual Process Theory.

#### **D. Conclusion**

The study of theories of developmental psychology has highlighted a number of issues relevant to this thesis. We have established that Piaget's work can be used in a way which gives consideration to the child, rather than correction of the child. Erikson's work contributes to knowledge of a child's social development and though rather specific, it is still significant in showing how the dynamics of this social development contributes to the construction of meaning by the child. Bronfenbrenner's Bio-Ecological Theory provides the infrastructure for the content, location and manner of connection from which children construct meaning from their surroundings. Bronfenbrenner also sets out the general dynamics for what might be expected in the setting for a SAT, the details of which are explored in Chapter 3. There is a link between how we understand children and how we relate to them and there is a strong possibility that these can be conceptually integrated with each other. However, if this is to be achieved a conceptualisation and associated terminology are needed which take account of the complexity of childhood spirituality and are appropriate to the clinical context in which it is applied. The terminology of transcendence rests on a different conceptual basis and needs to be replaced by a concept that can be expressed in a way that reflects the focus on the developmental and contextual dimensions of children in healthcare and describes the meaning they present during the use of a SAT. Combining the above theories gives an insight into the complex nature of childhood spirituality and avoids the shallowness of depending on a single theory. However, in order to discover this and for someone to relate to a child, child development still has more to offer and Bronfenbrenner's work has pin pointed some ways that include the ecology of the child. However, a more detailed theoretical basis is required to know what is involved in an encounter with a child in order to identify how it might be applied specifically in the use of a SAT.

## **Chapter 3: The role of play and the place of story**

### **A. Introduction**

This chapter will develop the building block identified in Chapter 2, to provide for the construction of a conceptual framework for children's spirituality. Further exploration is required to understand more about the content and features of Bronfenbrenner's 'dyadic link', concerned with the child's connection to another person. In order to discover what this connection might involve, this chapter will explore the significant contribution to child development theory made by Vygotski's<sup>102</sup> Social Cultural Theory (Howe and Mercer 2007, p.4). If his work offers the insight required, then a crucial stage will have been reached in understanding how development affects a child's spirituality and how to relate and engage with a child to construct a child's sense of meaning. Additionally, I draw from Myers'

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<sup>102</sup>Lev Vygotski (1896 – 1934) was a Soviet psychologist who was considered to be the founder of cultural-historical psychology. In his lifetime, the Soviet government was unsympathetic to his work and it was suppressed. In recent years, Vygotski's work has become influential in education in the Western world (Veer, R. van der and Anton Yasnitsky, A. (2011).

application of Ritual Process Theory to enhance the understanding of how to relate to children and how they construct meaning at different stages of development. The exploration of the work of Vygotski and Myers is the final part in the first step towards developing an interpretative framework for spirituality and the selection of a methodology within which childhood spirituality can be studied is the second step. Bronfenbrenner makes reference to play and storytelling being a means to that end (Bronfenbrenner, 1979, p.47).

Play and storytelling are possible methodologies to apply the theoretical measures identified in the first step. If this is to be achieved, four aspects need to be considered. Firstly, while Vygotski's work will provide the principal basis for understanding play, an outline of other perspectives on play from the field of child development will provide additional insights into what is taking place during play. Secondly, an overview of the type of play used for research purposes may provide an awareness of the culture of play with which children engage, whether free or focused. Third, it will also be useful to look at a more focused model of play, how it can be used towards a therapeutic outcome, and to observe how professionals engage with children through play. Fourth, if storytelling is a method that supports Bronfenbrenner's idea of a dyadic link, then an exploration of the work of Susan Engel, a developmental psychologist in storytelling, could suggest how children construct story and adopt the role of storyteller. This may assist in identifying specific expressions of this dyadic link which offer guidance as to how to engage appropriately with a child using such an approach. All four aspects may offer insight into a how a methodology based on play and storytelling can make a point of connection with a child and offer insight on how theory can move to practice.

## **B. First Step: A Theoretical Platform**

### *1. Lev Vygotski*

#### *a. Background*

Keenan states that:

Vygotski believed that the child's social environment is an active force in their development, working to mould children's growing knowledge in ways that are adaptive to the wider culture in which they grow up (Keenan, 2005, p.132).

Whilst Bronfenbrenner offers a psychological framework of how children can construct an increasingly complex and meaningful understanding of their surroundings, Vygotski addresses the social dynamics of the context in which that takes place. Related to the dynamics of Bronfenbrenner's 'dyadic links', Vygotski's work focuses on a child's connection with someone and the meaning children have made in order to provide a sense of connection which might allow them to be able to share information. In this thesis, this would relate to the quality of the connection established between the healthcare professional and the child during the application of the SAT.

Vygotski was a Soviet psychologist whose early 20<sup>th</sup> century work was not fully appreciated until it was translated and read by those in the West. His Cultural Historical Theory provided foundational principles that have enabled teachers to achieve more effective learning in children. Concerned with thinking, reasoning and memory, the primary focus of Vygotski's developmental theory is that, "mental functions have social connections" (Santrock, 2007, p.228). Coming from a Marxist perspective, Vygotski proposed that the economic collectivist principle of shared goods is paralleled by the shared and collective cognitive development of children; that a child's development takes place in a social setting and through social interaction. As such, child development has what Davydov called a "historical character, content and form" (Davydov and Kerr, 1995, p. 15) where "psychological tools" such as speech and language are key in how children learn and develop.<sup>103</sup> Vygotski proposes that:

Children not only speak about what they are doing: their speech and action are part of one and the same complex psychological function, directed at the solution at hand... Children solve practical tasks with the help of their speech, as well as their eyes and hands (Vygotski 1978, pp.25-26).

In this approach language is viewed not just as means of social communication, but as the social cognitive construction of meaning itself. The social interaction of solving problems through the articulation of thought processes, then leads to the process of internalisation of dialogue and out of this, learning and development occur.

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<sup>103</sup> This is a distinct advantage of this theory as it is situational. It places the child at a certain point of their development in the world.

The key feature in achieving this internalisation is the Zone of Proximal Development (ZPD). Vygotski states that:

The zone of proximal development defines those functions that have not yet matured but are only in the process of maturation; functions that will mature tomorrow but are currently in an embryonic state. Those functions could be termed the “buds” or “flowers” of development rather than the “fruits” of development. The actual development level characterises mental development retrospectively, while the zone of proximal development characterises mental development prospectively (Vygotski 1978, pp. 86-87).

Santrock summarises the ZPD as being “Vygotski’s term for the range of tasks that are too difficult for the child to master alone, but that can be learned with guidance and assistance of adults or more skilled children” (Santrock, 2007, p.228; Keenan, 2005, p.133). These more skilled children are called “experienced other(s)” and their shared knowledge facilitates the fulfilment of the learning potential of others.

Closely associated with the ZPD is the concept of “scaffolding”,<sup>104</sup> where the level of support for learning and development is initially stronger and is then adjusted to fit the child’s performance. The use of dialogue in scaffolding a child’s learning enables the child to encounter a more organized and systematic understanding of a subject and also to possess new information about himself that previously would have been unattainable.

The concept of “self-talk”, where children verbalise their thoughts, highlights a contrast between the approaches of Vygotski and Piaget. Vygotski considers self-talk as a means to learn and search for meaning, through the connections being made in the act of speech; whereas Piaget considers this self-talk as being egocentric speech, where children test existing knowledge in a search for equilibrium and that they do not have the capacity to understand it. Agreeing with Vygotski, Keenan proposes that:

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<sup>104</sup> Scaffolding is a term used by cognitive psychologists to describe and develop the international support that was conceived by Vygotski. A key proponent of this term was Jerome Bruner a cognitive psychologist.

Language gives children the means to reflect on their own behaviour, to organize behaviour, and to control their behaviour. Children's speech to themselves reflects the fact that their thought is organized in the form of dialogues with others and because thought is dialogic, the language which supports it gets expressed (Keenan, 2005, p.135).

Vygotski's concepts of ZPD and scaffolding offer a way to understand the significance of the interaction between adult and child during a learning process. Dialogic interaction increases children's sense of identity and awareness, enabling them to make sense of their given context.

*b. Insight*

Vygotski's approach suggests that learning should not be a value-based task where judgment is made on a child's development; nor should it be a task where a child is viewed as bad, non-cooperative or unintelligent. Instead, the learning encounter is viewed as a problem-solving activity where adult and child come together to learn, with responsibility resting with the adult to address the learning opportunity.

Like Piaget, Vygotski believed that children are active participants in shaping their own knowledge but for Vygotski, the determining factor is the context not the individual. Nature, nurture and particularly biological and cultural forces "coincide and mingle with one another...the two lines of change interpenetrate one another and essentially form a single line of socio-biological formation of the child's personality" (Vygotski in Wertsch, 1985, p.41). For children to develop as they should an appropriate learning environment is required, and it should also be used appropriately. As children are active agents in shaping their own knowledge, they also have the capacity to influence the learning environment, often creating momentum through their innate sociability.

Vygotski suggests that learning is more effective within a social context. While a child in isolation may learn and develop, research indicates that a child's learning and development is enhanced as a result of working alongside a "significant other" such as a teacher (Dolya and

Palmer, 2004, p.16).<sup>105</sup> He emphasises the role of language as an important part of the process of learning and development.<sup>106</sup>

### *c. Critique*

Vygotski stresses the social-cultural setting and its impact on the development of the child. He pays close attention to the individual child's needs, allowing a greater sensitivity to the specific development of the person. However, in terms of understanding child development he does not provide a universal model against which a child can be measured, as do the stage theories discussed in Chapter 2. The learning experience is conceptualised in terms of an individual in a cultural setting, rather than in terms of progress made through stages of development. As such, in an educational setting Vygotski's theory may not provide an account of longitudinal progress, but this focus is well suited to the exploration of the needs of individual children at a specific point, as studied in this thesis. His emphasis assists in understanding how the processes of engagement with a child can engender an effective learning environment.

However, there are potential difficulties related to the role of adults in the ZPD. In creating an effective learning environment it is possible that the adult facilitator may be too helpful, making the learning process so easy for children that they are unable to internalise what they have learned. If children expect to receive help they may not feel the need to try, thereby reducing the level of collaboration between adult and child. Adults responsible for educating children must be fully aware of the nature of their role. In comparison to other theories, Vygotski's is arguably vague in understanding the development of the child overall; in its lack of prescription of how a ZPD should be constituted to be a good learning context. It is important to investigate how the ZPD can be understood in relation to stage theories, and to investigate if the ZPD is perceived only by the adult, only by the child or mutually by both.<sup>107</sup>

### *d. Application*

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<sup>105</sup> This has implications for the SAT. If it is conducted with another person the child is more likely to grasp and understand what is being sought than to deal with it on their own.

<sup>106</sup> If this is the case in terms of this thesis then the articulation of a story during a SAT might facilitate in the connectedness of the child as they understand the meaning of their lives as they comprehend their own understanding. This does not mean that an assessor of a SAT is asking of a child to express their views but rather to construct their views.

<sup>107</sup> These are important questions to consider further into the thesis, especially the mutuality of what is taking place.

Vygotski's Zone of Proximal Development (ZPD) offers insight into a very specific aspect of this thesis. The idea of a ZPD focuses only on the process of meaning construction. It does not provide for the content of meaning, as does Bronfenbrenner's theory, but it suggests an environment that is conducive for information to flow more freely between the healthcare chaplain and the child, allowing children to connect effectively with an "experienced other" in order to explore information about their spirituality. An assessor could use Social Cultural Theory as a framework to consider the most effective context for a child and assessor to work together using the Spiritual Assessment Tool (SAT), and in doing so provide a basis from which to consider the most effective design and use of the SAT. Vygotski's theory is especially significant in understanding the nature of the encounter between the assessor and the child. There is a ZPD between the child and the assessor, but it is vital to understand what is taking place in that zone and how it can be described.

This point of proximity exists in the midst of a hospital environment where children's experience on their healthcare journey can result in them feeling very vulnerable. The hospital setting may offer a better quality of life or it may, regrettably, add to an already harsh experience for the child; either through the nature of the treatment or the actual environment itself. As such, an encounter between child and assessor should take place in an environment which has the capacity to become a means to trigger a child's exploration into a spirituality, which otherwise would have been too difficult for a child to explore. On the basis of Vygotski's "significant other," the SAT encounter requires the presence of a trained professional assessor who can enable a child to make connections, not just with assessor, but with their own thoughts and the people around them. This diagnostic process is made possible, and is more appropriate, if a SAT is conducted in a therapeutic manner.

Vygotski's emphasis on the importance of the social environment for a child's learning experience, presents helpful insights to understanding the most appropriate ways to explore the spiritual framework of a hospitalized child. Vygotski indicates that a child's learning capacity can be enhanced and it is proposed, in this thesis, that there are ways to enhance a child's willingness to share critical information through the use of a suitable SAT by a trained assessor who is an "experienced other." Based on Vygotski's concept of ZPD, there is the potential for a different approach to spiritual care that creates an environment conducive to children articulating how they construct meaning. In the healthcare setting, the developmental stage theory approach has tended to be the predominant approach to the categorization of

children's spirituality. Vygotski's concept of ZPD offers a model of engagement with children which is more sympathetic to their spiritual ecology. While Bronfenbrenner provides the background and middle ground of children's ecological world, Vygotski gives the sharpness and detail of the foreground of the mechanism to the immediate ecological setting where children are enabled to share what is meaningful to them.

A new conceptual construct for childhood spirituality must be understood within a context that enables a child to connect with that context (Estep et. al. in Ratcliff (ed.), 2005, p.337). We must explore the context required to allow a SAT to be conducted in a manner that creates a proximal zone conducive to a child being able to share information. The context in this study is the healthcare setting, where professionals seek the health and well-being of children. The healthcare context must be prepared for the use of the SAT which must also be accepted by parents, who serve as gatekeepers to the children. The SAT must be administered by a healthcare professional who can engage effectively with the children. This is a crucial aspect as the assessor serves as "the significant other." The skill set possessed by the healthcare professional to create this environment must be apparent to children, families, and the healthcare team (see discussion of competences Chapter 8).

## *2. Barbara Myers; Ritual Process Theory*

Barbara Myers, in her book *Young Children and Spirituality* (1997), seeks to make spirituality accessible to the secular world by describing the engagement of staff with children in a special educational centre. She uses Ritual Process Theory with Vygotski's ZPD, making a comparison between the two in order to identify four core conditions which are transferable to a secular context. Although focusing on preschool children, the four conditions used to explain how a young child might move from the known to the unknown in the acquisition of knowledge have applicability to this thesis.

Myers' application of Turner's Ritual Process Theory (Turner, 1995, p.ix) combines her first core condition of "hospitable space" with Vygotski's "zone of proximal development." In doing so, she describes a process that leads towards an understanding of a child's transcendence, whether that is a symbolic ritual of a faith community, or a child's daily routine for sleep (Reich, 2000, p. 216). There is an aim, common to both theories, of engendering a space that is familiar for the child. Myers identifies the first element of Ritual

Process Theory, the “invocation of sacred space”, with Vygotski’s “zone of proximal development”. The “invocation of sacred space” is described as a space co-created by two people to generate a sense of transcendence.

The second core condition is what Myers refers to as “liminality”. Myers describes a liminal space as being where times of regular activities are set, such as an arranged eating time for a group of children supervised by adults; so that boundaries such as personal safety are maintained. Myers notes that these activities “ceremonially preserve certain patterns as they provide occasions in which the dynamics of transcendence can occur” (Myers, 1997, p.78). Were this condition to be applied to conducting a game or relating a story, a child and adult could create a liminal space between them where they each conform to the parameters of the activity.

The third core condition is the role of the ritual elder, and this is linked with what Vygotski called “the significant other”. Ritual elders, according to Moore (1984), establish the sacred space and deal with “boundary issues, assure safety and provide direction and closure” (Myers, 1997, p.83). Moore refers to ritual elders as being the “technicians of the sacred” (Moore<sup>108</sup> in, Moore and Reynolds (eds.), 1984, p.136). The way ritual elders co-construct reality corresponds to Vygotski’s concept of “scaffolding” (Myers, 1997, p.83).

The fourth core condition is the “expectation of transcendence” (Myers, 1997, p.79). Myers provides a description of this that is similar to Vygotski’s on the basis that, in the context of learning, Vygotski’s theory seeks to move from the “known to the unknown”. In the Ritual Process Theory this is identified as “a presence of the ultimate that is beyond the immediacy of the moment within such sacred space” (Myers, 1997, p.82).

By comparing Ritual Process Theory and Vygotski’s theory, Myers identifies four core common conditions which define the functional nature of spirituality, and enable spirituality to be accessible to the secular world; “hospitable space”, “recognition of experience”, “adult presence” and “expectation of transcendence” (Estep et al. in Ratcliff (ed.), 2005, p.338). Myers understands hospitable space as a setting that is secure and safe; where children can

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<sup>108</sup> “Space and transformation in human experience” p.136

process their feelings (Myers, 1997, p.64)<sup>109</sup>. Recognition of experience allows a child to have experience which is not controlled or determined by others; it acknowledges that a child brings and obtains experience in a given context (Myers, 1997, p.65). The third core condition, adult presence, is understood as the presence of a professional adult who is able to engage with children in the classroom through a “dialogical connection”<sup>110</sup> (Myers, 1997, p.65). Myers states that transcendence is “to name a process of going over, beyond, or through various limits or obstacles” (Myers, 1997, p.11, 67). The process of learning is to anticipate that there is something to be discovered and in relation to Myers’ application the process of learning is to bring hope to people as they embark on a journey.<sup>111</sup> These conditions are the criteria for an environment that she calls an “intersubjective space” where “co-constructed knowledge” is developed (Myer, 1997, p.69).

As with Vygotski’s theory, educators have found it difficult to look at the overall development of a child from Myers’ perspective<sup>112</sup>. This is the case also with Myers’ understanding of the basis of human existence as drawn from the nature of the encounter she discusses; the insight drawn from research with one particular group does not necessarily reflect how the rest of humanity functions. There is a strong connection made between Vygotski’s concept of the ZPD and Myers’ application of Ritual Process Theory, in that both focus on the process of transcendence rather than the person; there is insufficient discussion on the personhood of the child within the process and the nature of the experiences brought by the child to the processes.<sup>113</sup> The potential inequality of the encounter between adult and child might also be considered as a difficulty. If the adult holds the balance of power, as they do in her conception of liminality, this has the potential to result in a paternalistic situation where the child feels it necessary to comply with the adult’s lead. There is also an assumption that the child and the adult will experience compatibility in the encounter. Myers’ last core condition for learning, the “expectation of transcendence” is not present in Vygotski’s ZPD

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<sup>109</sup> Myers’ draws from Henri Nouwen’s work where he says it, “ ‘is our vocation to convert the host is into hospes (Greek words).’ This is to say that our work as humans is to convert the ‘enemy into a guest and to create the free and fearless space where brotherhood and sisterhood can be formed and fully experienced” (Nouwen, 1975, p.46) Reaching out: the three movements of the Spiritual life, Garden City, New York: Doubleday

<sup>110</sup> This is a term that she uses from Erikson’s works and refers to the cog-wheeling process of relational interaction between the child and others. The adult is to be able to reciprocate in a similar way.

<sup>111</sup> Myers draws from the work of P. Phenix (1974) Transcendence “suggest(s) that all learning involves moving from what is known towards what is yet unknown.” (Myers, 1997, p.66)

<sup>112</sup> Her focus was on a certain age and in relation to Piaget’s theory one stage and not the development of one stage to the next.

<sup>113</sup> This has significance for the SAT at several levels. It could be that a child encounters the SAT after many visits to hospital, or that it is conducted near the end of their hospital stay, or that their “stage” in development accounts for different approaches or responses to the healthcare journey.

terminology; although there is a conceptual correspondence with Vygotski's ZPD seeking to move from the known to the unknown. This suggests that conceptual frameworks may be used to adopt and transfer psychological theories in order to explain different contexts.

Myers has adopted a concept of the process of transcendence that is understood as "the essence of who we are as humankind" (Myers, 1997, p.101). She draws her explanation from Fowler's understanding of transcendence (Myers, 1997, p.103; Fowler, 1981, p.14). This understanding of transcendence introduces a conceptual framework that constructs meaning in a way incompatible with the attributes already identified as the building blocks in the conceptual reconstruction of childhood spirituality, and the terminology appropriate for a healthcare setting. It is necessary to understand the experience of the interpretative narrative from the perspective of the individual (Woodgate and Kristjanson, 1996, p.282; Woodgate and Degner, 2002, p.195; Woodgate, 2006, p.11). However, the concept of transcendence imports meanings more suited to a religious context. Is it not conceivable that the same experience and reality could be considered another way? Myers may identify some sense of meaning by referring to transcendence, but as transcendence is generally viewed as a term used in relation to 'religious' experience, the use of the term may interfere with the possibility of the underlying concept of transcendence being recognised in a secular context. In trying to explain this phenomenon, we must ask what is within a person where there is a gravitational force for meaning, or what Fowler has referred to as the "ultimate concern". Myers and Fowler have followed a direction that has become generic but has theistic roots. Is this, like transcendence, another case of inherited language where the meaning is outgrowing the term used? Is there a need to refer to transcendence? What is in a person's life that causes them to gravitate towards these aspects? It may not be what is beyond them, but rather, what is within them that generates such momentum. Why does a child want to connect?

In Myers' discussions, this is explored further through the term, "invocation".<sup>114</sup> When this is considered in connection with the key features of Ritual Process Theory, the hospitable space is considered to be brought about by "invocation"; an aspect of intent in this hospitable space. Just as learning something new is the intent of Vygotski's ZPD so, for Myers, transcendence is the outcome of the ritual process. The concept of "transcendence" in Myer's theory goes

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<sup>114</sup> If a 'new child discovers things in the new 'place' that are similar yet dissimilar from those at home, 'invocation' is about connecting the two and giving permission to enter and to feel comfortable with the 'new space'." (Myers, 1997, p.80)

beyond the boundaries of this thesis. However, it does describe a process which re-applies Vygotski's theory, and as such, can be transferred to correlate with the emerging conceptual framework in this thesis; that the combined capacity of the child and adult in a SAT encounter leads to an increase in the assessor's awareness of how a child's spirituality has been constructed.

Play and storytelling would be expected to assist in this engagement between child and adult;<sup>115</sup> allowing a child to feel emotionally open in a familiar, safe space. Myers indicates that the four core conditions are conducive to how to discover what is currently termed as childhood spirituality. She describes the interplay between these conditions, noting that:

When I claim four core conditions as necessary for a community to embody a spirituality of caring in the lives of young children, I am arguing that out of all possible conditions these are the most helpful. While I have discussed four conditions, no linear progression is implied. They all need to be present in overlapping, mutually informing ways (Myers, 1997, p.106).

It is important, when conducting a SAT in a manner consistent with Myers' proposals, that these core conditions are met in order to allow children to narrate their lives in a manner that reveals the complexity of their spirituality.

The insights gained through combining Myers' application of Ritual Process Theory and Vygotski's theory of the ZPD, can aid understanding of the primary core conditions required to create a setting more conducive for a child to share information, and to place the healthcare professional in a place of discovery. These conditions require that the child feels a sense of security; that there is an acknowledgement of the child's experience before and during hospitalisation; that an adult healthcare professional or parent is present; that children feel able to share what is meaningful to them in hospital; and the healthcare professional listens actively and has an appreciation of the child's ecological environment.

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<sup>115</sup> This would mean that the adult also has to be in a place that they are emotionally open.

While Bronfenbrenner's broad contextual framework to construct meaning is critical to acquiring the content of that meaning, Vygotski offers a clear insight into the interaction needed to generate shared meaning. The comparison of Ritual Process Theory and Vygotski's theory of the ZPD, suggests that just as there is a zone of proximal development in the education of the child. As such there could be a new focus for a similar zone that is specifically conducive for children to share what is meaningful to them and for an assessor, such as a chaplain, to construct how children present their spirituality. This specific zone of proximal development is where interaction between the child and adult would take place when using the SAT. It provides a context for an encounter; a connection that enables children to articulate and express information about their lives and the opportunity for an exploration of the dynamic nature of that information and how it is framed and presented to others. The adult must clearly re-present that information, so that it is not misinterpreted or misrepresented. Combining Vygotski's Social Cultural Theory and Myers' Ritual Process Theory has made it possible to identify core conditions to create the zone in which the SAT encounter should take place. Through the encounter with the healthcare chaplain as assessor, children can increase their capacity to share what is meaningful to them while in hospital and the assessor can identify their sense of connection or disconnection. Vygotski's ZPD provides the detail for a setting where a child feels able to share information. Myers' work on Ritual Process Theory and Vygotski's ZPD lays down the theoretical basis for the design of the SAT to engage and connect with a child, and lays the basis of what is required where such engagement takes place.

The discussion now turns to methodology and how Ritual Process Theory finds its expression in the role of play and storytelling, and how they might be the means for putting theory into practice.

### **C. Step 2 Methodology; The significance of play and storytelling for enabling meaningful connections in childhood spirituality.**

#### *1. An Introduction*

Research has found that children respond well to the use of play and storytelling in terms of establishing a relationship (Ward, 2005, p.91; Santrock, 2007, p.508); in acquiring new knowledge in an educational setting (Palmer, 2004, p.6; Rich, 2005, p.12); for therapeutic

purposes (Amer and Hayes, 1999, p.91; Landreth, 2002, p.16) and in a research setting (Barter and Renold, 2000, p.308; Carroll, 2000, p.11; Koch, 1998, p.1182). These findings suggest that play and storytelling should be considered as potentially useful ways of creating “proximal processes” between a child and a professional assessor when conducting a SAT (Boyatzis and Newman 2005, p.169-176).

## *2. The Role of Play*

The world of child is the world of play, even when hospitalised  
(Haiat, 2003, p213).

It is evident that play is still a significant part of a child’s life when in hospital. Play can be used by the healthcare chaplain as an assessor so that they can understand the paediatric patient’s new world, and the skills required to engage with it. The chaplain is part of an environment which has a diversity of play facilities. The presence of such varied opportunities for play can sometimes confuse the child as to the role of some play and so the healthcare chaplain has the responsibility to retain the child’s focus.

### *a. An Outline - Further insights from child development*

The role of play can be explored by examining the importance that child developmental psychologists attach to it as a way for a child to connect with people and objects around them. The child psychologist, Dr. Thomas Keenan, provides a definition of play:

Classical theories of play saw it as a means of exercising skills that will be required later in life. In essence, play is an instinctive way of acquiring and rehearsing future skills (p.201, Keenan, 2005).

Although acquisition and rehearsal of adult skills may be one characteristic of play in children, the continuance of play into adulthood would suggest that it is an aspect of humanity that is not dispensed with in adult life. Play is considered by others, not just as a child developmental technique to rehearse skills for life, but as a continuous strand in a

person's approach to understand, and engage with, their surroundings (Berryman, 2002, p.43; Berryman in Ratcliff (ed.), 2005, p.39; Ward, 2005, p.91).<sup>116</sup>

Piaget, Bronfenbrenner and Vygotski offer different insights into the multi-faceted nature of play. For Piaget, play is an activity which, although influenced by the cognitive stage of a child, also helps to develop a child's cognitive skills in a relaxed setting. Piaget defines one of the earliest stages of play as being 'sensorimotor and practice' play; where infants are, in effect, "exercising their sensorimotor schemes" using the building blocks for cognitive development (Santrock, 2007, p. 507). In Piaget's concept of *equilibrium*, the repeated exercise of a child going down a slide would enable understanding of what was required, reinforced by practice.

Usha Goswami and Peter Bryant, in their interim report for *the Primary Review on Children's Cognitive Development and Learning* in 2007, state that "Vygotsky regarded play as a major factor in cognitive development" (Goswami and Bryant, 2007, p12). Based in a Russian social and political context, Vygotski considered imaginative play to represent "a specifically human form of cognitive activity" (Goswami and Bryant, 2007, p12). This contrasts with the thinking of western psychologists where play is seen as a rehearsing of a deeper understanding of the mind. Vygotski views play as a social rehearsal where children learn to "act against their immediate impulses and follow 'the rules of the game' (Goswami, 2007, p12)<sup>117</sup>. Keenan also highlights this aspect saying that "pretend play tends to be based on rules ... children's play is constrained by the rules which guide behaviour in these roles, and because of this, they learn about the social norms that are expected of people" (Keenan, 2002, p.135).<sup>118</sup> Play can be seen as increasing the child's ability to enter a virtual world and engage with it by using the rules taken from the real world. This can be seen in children's

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<sup>116</sup> "Children are not adults. Adults are not children. Adults, however, can become like children and over time such adults can nourish children to become even more like children as they mature. This is not madness. It is the pathway of infinite progress into the domain of God. All else is infinite regress." Berryman, in Ratcliff, 2005, p.39

<sup>117</sup> In terms of a child's stay in hospital, these new surroundings are like entering a new game where they are unfamiliar with the rules until they are explained by the adults who care for them whether they be family or professionals.

<sup>118</sup> An article indicated how those social norms can be affected by those who facilitate play with children (Joyce, 2005, p.5)

sense of anticipation of their connection with how they imagine their virtual world might be; for example a child might ask, “What will my hospital experience be like?”<sup>119</sup>

Trudge, a commentator on Bronfenbrenner, has referred to play and aspects of storytelling as a way for children “to make sense of their world and understand their place in it, and both play their part in changing the prevailing order while fitting into the existing one.” (Trudge et al., 2009, p.200). Bronfenbrenner’s perspective is more relevant to understanding a child’s social setting than Piaget’s developmental theory, which seems to focus more on the psychological process of a particular child’s cognitive abilities. While Piaget’s theory might be applicable in an educational setting, the approaches of Vygotski and Bronfenbrenner relate more specifically to a child’s engagement with their surroundings, and in particular their dialogue with others.

#### *b. Insight*

The role of play can be interpreted differently dependent on the understanding of the nature of a child’s cognitive development. Children’s repetitive activity is viewed by Piaget as a means to develop their mind and improve their skills. Vygotski understands the role of play as a means for the child to understand and relate appropriately to their surroundings; his model is primarily concerned with the social setting of the child. Bronfenbrenner takes this model further by observing the complexity of how social links are formed between the different systems that make up the child’s world; for Bronfenbrenner, play is an interaction with someone from another context, that helps them to explore what is in that other context, or reminds them what is there.

#### *c. Critique*

Although the theories of Piaget, Vygotski and Bronfenbrenner offer different perspectives on the role of play, insights from their theories can be combined to offer a comprehensive perspective. Bronfenbrenner identifies play as one of the links between the systems he devised, but unlike Piaget he does not examine the longitudinal development of the child. Vygotski does not elaborate on the developmental differences between children of different

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<sup>119</sup> This is for example anticipated through the Preadmission Service based at Yorkhill where paediatric patients, at pre-admission stage, are given the opportunity to see, where treatment is taken place and what equipment will be used. This is cited in the NHS Greater Glasgow and Clyde Equality Impact Assessment Tool For Frontline Patient Services [http://www.equalitiesinhealth.org/documents/Pre-AdmissionserviceYorkhillWCDirectoratefollowingQA2\\_000.pdf](http://www.equalitiesinhealth.org/documents/Pre-AdmissionserviceYorkhillWCDirectoratefollowingQA2_000.pdf) (identified on the web - 10/1/12)

ages, and Piaget does not fully address social awareness in children and their use of play to engage with the world. Each theory adds something to our understanding of the complexity of this multi-faceted phenomenon.

#### *d. Application*

None of these perspectives can be ignored when attempting to understanding why a child might engage in play. When a healthcare chaplain uses a SAT portfolio, he or she should be able to account for the multiple-dimensional nature of a child through the design of a tool that is able to draw from all perspectives. It is important to be aware of a child's cognitive level in order to gauge if the SAT can be understood by the patient, and this has a bearing on the choice of age spectrum of the children selected for the research sample. Bronfenbrenner's approach offers the potential of taking a broader view of the links a child has to make to be aware of, and make sense of, the world that shapes them. Vygotski's social theory has the capacity to offer insight into the interaction that takes place between the patient and the professional. If play is to be used as a means to connect with a child, and if a child is to be able to communicate their perception of the world in a safe environment, then exploring other ways that play has been used in a healthcare setting may help to identify what role play should have in a SAT portfolio; it is important that the role of play is relevant to the understanding of spirituality as outlined in this thesis. As such, the models examined should relate to how play is used in paediatric healthcare, including the hospital context in which this research takes place.

### *3. The use of play in healthcare and therapy; insights for this thesis*

#### *a. The healthcare context*

Israeli nurse, Hana Haiat, examined the ability of nurses to make play effective in the hospital setting. She asserts that nurses should acknowledge the importance of play, observing children's play to ascertain what is enjoyed and communicated through play. Haiat et al., observed a child's healthcare journey to plan for how play can be integrated into their interactions with children in a variety of situations; from routine measurement taking, such as blood pressure and pulse, to preparing for and carrying out painful or unpleasant procedures (Haiat, 2003, p.213). This approach integrates play into the world of the hospitalized child and helps to make staff accessible. As a result children are more easily able to connect with

an unfamiliar context, and to explore in their mind and imagination what the impact of that context might be. By using play the child may develop the skills necessary to cope with a difficult hospital experience. In Haiat's study, play was used as a means to gain a child's trust and to build a relationship with a child in order to help her understand the hospital context

#### *b. Play at Yorkhill Hospital*

The data collected for this thesis was collected in Yorkhill Hospital, and a description of the play activities that already exist in the hospital will provide information on what play might mean to a child in this setting. The hospital provides a number of services which offer play to children. Firstly, the Play Specialist Team<sup>120</sup> provides a range of toys appropriate to a child's stage, from toy animals to computer games, in addition to supervised and unsupervised craft activities. The team also uses play as a means to explain intrusive and painful medical procedures (particularly injections), to alleviate children's distress and help them to understand what is happening (Taylor, 2004, p.21). The team also provide play activities such as craft work, which are used to encourage a child's recovery process by improving hand co-ordination and acting as social and mental stimulus. Youth Services are provided for young people aged over 12, with a range of music, computers and computer games being available. Many of the facilities for older children are accessed in a room called Zone 12+ on the seventh floor of Yorkhill Hospital.

The play facilities in Yorkhill are similar to those described by Haiat et al., who describe a set up in Israel called the Starlight Hall, although internet access is also provided for the young people so that they can speak to their classmates.<sup>121</sup> Haiat et al. provide an assessment of the activity room that is also relevant to the Yorkhill context:

The activity in the room is based on the assumption that when children are occupied in a variety of activities, they tend for a while to forget their pain, feel better, and, in some instances, require fewer pain killers (Haiat et al., 2003, pp.212-3).

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<sup>120</sup> There are further education modules available for nurses to have placements with play specialists in a paediatric setting <http://www.modules.napier.ac.uk/Module.aspx?ID=CHN07103>

<sup>121</sup> Since the start of writing this thesis certain areas have internet access provided by the hospital. I have also observed that some children have laptops with them with a USB "dongle" that offers internet access through a mobile network. Some children have used innovative ways to connect to friends outside the hospital through using online game consoles games where they use the game to communicate but the purpose of the game is redundant. This provides for them free internet communication.

This evidence of the successful use of play in improving children's hospital experience and enabling recovery suggests that play could be usefully incorporated into this study, allowing children to engage positively with an aspect of the hospital.<sup>122</sup>

Secondly, different play areas are available at Yorkhill hospital, and items such as a toy cupboard, pool table, doll's house or larger toys can be placed in a designated part of the ward. More specialised areas, called *snoezelen rooms*, are multi-sensory environments which make use of multi-coloured optical fibres, large shaped soft blocks, a ball pool and coloured lighting which projects changing images across the ceiling. This environment can be used to relax and calm a child or provide stimuli for a child with global or special needs. Haiat et al. describe the impact of a similar room on a child:

The white room influences the child because of its design and accessories, which allow for multiple stimulation of the senses. The room has a calming effect, it focuses and increases curiosity and the urge to investigate and discover . . . in the White room it is the child who stands at the epicentre and it is he who leads and directs all activities. It is here that the hospitalized child gains control over the situation, a control he loses during the course of illness and hospitalization (Haiat et al., 2003, p.212).

While this study will not deal with children with special needs,<sup>123</sup> it is relevant that play can enable and empower a child, creating a space of involvement and self projection where they have ownership of activity.

Thirdly, through the provision of spiritual care, I have observed the importance of play provided by the child and family. This can range from the provision of computer games to craft activities, comics, books, toy cars, figures or cuddly toys; indeed, sometimes a child is overloaded with toys from generous visitors. Children often spend time in hospital watching

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<sup>122</sup> What is this aspect of play that is disengaging from their current set of circumstances? Can this still happen when the focus is on the current circumstances?

<sup>123</sup> Refers to section that addresses the inclusion and exclusion criteria for recruitment

DVDs which, although perhaps considered more as entertainment, can often provide themes and stimuli for play with particular toys.

Fourthly, there is play between children which can be triggered by the child, the parent or the play specialist. This type of play demonstrates children's capacity to engage with their surroundings. A child who naturally engages with others may be able to interact through play with a healthcare chaplain. Through this play, it would be possible to observe how children connect to a context and how they make meaning of their world.

Fifthly, play therapists are employed to work with children to help them recover and remain stimulated during rehabilitation.

Examining the ways in which play is used as a means to engage with children may establish principles which could be applied when using a SAT.

*c. Insight from the practice of play in a paediatric healthcare setting*

Play in the hospital setting is only one element in a child's experience of play, the others being a child's parents and the play the child has experienced in the community. It does demonstrate that the healthcare environment encourages play as part of the child's surroundings.

*4. Critique of the use of play*

It could be argued that in certain circumstances, the use of play may confuse the child. If play is used to explain painful interventions, the question that arises is, "Will a child be able to differentiate between the different types of play used in the hospital?" Other types of play used by professionals, parents and children may have no purpose other than to distract and preoccupy the child. This may disengage the child from trying to understand what is involved in the hospital procedures. In the same way, a child would need to adjust to the form of play used in a SAT. While some play is used in order to distract the child, the purpose of play in this study is to explore the impact of the child's healthcare journey on the way in which they make sense of their surroundings.

*5. Application*

With a diverse range of reasons for the application of play within a healthcare setting, it is evident, from established practice, that when presenting a SAT for use with a child they should see what it is and understand what it is for. Otherwise there is a risk that there may be a measure of distrust and disinterest on the part of a child, who may have already experienced play in association with a painful intervention. The application of Myers' core conditions of the application of hospitality, liminality, the significant other and invocation, can serve as parameters of play, and a clear explanation to the child of its purpose would be required to dispel any uncertainty felt. This is important, as engaging with a SAT would be voluntary and children should view it as something attractive to be willing to take part.

Using a SAT which is not age and stage appropriate may result in a child becoming disinterested in the process. The nature of play that children generally experience in a paediatric setting may raise their expectations that any form of play initiated will contain a high level of entertainment. As such, irrespective of the play activity offered, a child may choose to disengage from the process if the form of play does not meet that expectation. However, despite these potential problems, it seems likely that more information will be drawn from the child with a SAT using play, than from one that doesn't use play.

The healthcare chaplain acting as assessor should also be aware that a child's attention may be caught up in the entertainment component of the play element of a SAT, and that this has the potential to deflect the child from SAT's intended purpose. While a child may gain control in play it is important that the child, and the assessor, do not lose sight of the reason for that play taking place. The assessor should be aware of their responsibility to ensure that the play environment is appropriate to ensure that the SAT can be successfully utilised.

This thesis seeks to demonstrate, through interviews with research participants, that play engenders an environment which helps a child interact with a healthcare chaplain in such a way as to provide an insight into the child's spirituality.

#### **D. The insights gained from play therapy understanding how play is developed in this thesis.**

##### *1. Introduction*

Used skilfully by professionals, play therapy can provide insight into how children relate to their world. The therapy itself is not the primary focus in this thesis, but rather, how play can be used to conduct a SAT in a safe and secure way. Amongst a range of play therapies<sup>124</sup> Daniel S. Sweeney and Garry L. Landreth's child-centred approach (in *Foundations of Play Therapy, published in 2003*) provides a useful example. It draws from the classic approaches of play therapy adapted by Virginia Axline<sup>125</sup> in 1947 from Carl Rogers's therapy model.<sup>126</sup>

I have selected this approach as person-centred care is a predominant focus in the healthcare profession<sup>127</sup>, and it engages with play using an interpretative framework in order to understand the child. By examining this approach, I will draw from the similarities and differences between play therapy and my proposed approach, to identify appropriate features to develop a SAT that is suitable for the child, the healthcare chaplain and the context of an institution which issues policies in order to create a culture of care. It will also allow for the establishment of the parameters required for a SAT to be effective in a context where person-centred care is delivered.

While Sweeney and Landreth's approach has an intentional therapeutic purpose, the SAT in this thesis is designed to be more diagnostic. It may result in therapeutic benefits, but these are not its primary purpose. Stressing the person-centred aspects of play therapy, Sweeney and Landreth note that:

This child-centred play therapy centres on children. The role of the therapist in this model is not as a diagnostician and therapeutic director but rather a facilitator and fellow explorer on a journey with a child on

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<sup>124</sup> Other play therapies include - Narrative play therapy, Solution-focused play therapy, Experiential play therapy, Release play therapy, Integrative play therapy, Psychoanalytic approaches to play therapy, Child-centered play therapy, Gestalt play therapy, Family play therapy, Cognitive behavioral play therapy, Prescriptive play therapy

<sup>125</sup> Virginia Axline was a psychologist and one of the pioneers in the use of Play Therapy. (cited on the web 10/9/12 - <http://www.playtherapy.org.uk/AboutPlayTherapy/AxlinePrinciples.htm>)

<sup>126</sup> Carl Rogers was an influential American psychologist and among the founders of the humanistic approach to psychology. Rogers is widely considered to be one of the founding fathers of psychotherapy research. (cited on the web 10/9/12 - <http://www.simplypsychology.org/humanistic.html>)

<sup>127</sup> Person centred care is integrated into the educational agenda for the NHS in Scotland. The opening statement to this website states, "Person-centred care is providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions.

<http://www.evidenceintopractice.scot.nhs.uk/healthcare-quality-strategy/person-centred.aspx> (cited 26th June 2012)

a mission of self-discovery. (Sweeney and Landreth in Schaeffer (ed.), 2003, p.76)

Here the play therapists are suggesting that the child plays the role of the therapist in this process. In using a SAT, the focus is less on the child, but more on how the institution relates to the child and what its responsibilities to, or for, the child are; and how the chaplain can convey to others his findings about children's spirituality in relation to their healthcare journey. The chaplain can be viewed as having a facilitating role, similar to that of a play therapist, although there could be considerable variation in the level of involvement by different facilitators. Play therapists reach their conclusions by passively observing a child's play, not providing them with any direction.<sup>128</sup> The therapist provides an environment for play and through observation offers an interpretation of the child's play. In this process, the focus is on the observation made by the professional, analysing the child's play activity using their interpretative framework.<sup>129</sup> It is primarily used for gathering information and not as a means to self-discovery.

This model of play therapy has an "abiding belief in the child's ability to be constructively self-directing" that informs and shapes play therapy practice (Sweeney and Landreth in Schaeffer (ed.), 2003, p.76). This understanding of children as self-generating therapists does not completely correspond to the interpretative framework of spirituality in Chapter 2, although it is clear that having a settled view of a child does enable the professional to work in a consistent and focused manner. However, the play therapy model does not offer the flexibility required in a healthcare context which draws from a wider public. Referral for play therapy results from the status of a child's medical condition, rather than from the situational factors that might necessitate a spiritual assessment. The conceptual reconstruction of childhood spirituality requires greater flexibility, as one of the building blocks identified highlights that the encounter between a child and a "significant other" is a means of connection to create and discover meaning together. This model of play therapy is based on the understanding that the presence of an adult in the room does not influence the child's actions, and assumes that the child is detached from their surroundings. In this thesis it is

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<sup>128</sup> The assessor in this study acquires knowledge through focused play, using a card game which facilitates discussion. This latter interaction requires certain skills on the part of the assessor. This has implications for the competences required and the complexity of the task involved, See Chapter 8

<sup>129</sup> However, the SAT model is more interactive; the play is not with objects, but with symbolic cards which require explanation from the child.

acknowledged that the presence of an assessor can *assist* in the discovery of meaning through an encounter with a child. Based on Vygotski's concept of the Zone of Proximal Development, it is argued that this encounter between the professional and the hospitalised child is a meeting point where the construction of meaning can be nurtured and discovered. The presence of the assessor is an acknowledged reference point for the child who understands why that professional is present.

Sweeney and Landreth place emphasis on the positive context needed for a child's behavioural development. However, in reality a positive context is not always available to a child and they may need to have, or discover, a coping strategy to cope with difficult times (Pendleton, et al. 2002). If a child's health deteriorates they may have, in Piaget's term, a loss of equilibrium and a need to make sense of changed circumstances and surroundings. In play therapy generally, and the specific play techniques used in this study, a connection is made between children and the context within which they develop or construct meaning. Play therapy views development as a maturing process of becoming; "children can grow and heal when a growth-producing climate is provided for them, free from agenda and constriction" (Sweeney and Landreth in Schaeffer (ed.), 2003, p.77). This is a prescriptive definition aimed at the provision of a therapeutic outcome. However, this approach may be problematic in relation to this study, as the hospital environment is not always a "growth-producing climate" for children. The hospital has an agenda to cure, and constrictions may emerge related to aspects of treatment, or health and safety regulations, that are enforced to ensure that the health of the child is preserved or improved. However, some insight can be gained from the principles that emerge from a person-centred theory which, like Bronfenbrenner's theory, views the biology of an individual as "context". If a professional adopts a framework, the purpose of the framework is to enable the analysis of the purpose of the child's engagement with play. For play therapists, this framework is based on the fundamental constructs of Carl Rogers' theory which, in his terminology, involves the "person", the "phenomenal field" and the "self" (Rogers, 2003, p.136).

What Sweeney and Landreth refer to as the person is an entity within an individual which has experiences and perception built up through thoughts, feeling and behaviour; sometimes called "continuous dynamic intrapersonal interaction" (Sweeney and Landreth in Schaeffer (ed.), 2003, p.77). The aim of "being" or the nature of existence is "actualizing the self"

(Sweeney and Landreth in Schaeffer (ed.), 2003, p.77). In this context play is viewed as a means for a child to actualise themselves, and to be the person that they are.

Similar to the elitist conceptions of spirituality referred to in Chapter 2, Sweeney and Landreth's description of the actualisation of a positively functioning person is rather utopian. Whilst they are not advocating an evolution to perfection, the notion of actualisation does appear to be optimistic. However, there is a link to the interpretative framework of spirituality outlined in Chapter 2, in that it acknowledges that the person, in this case the child understood as a biological context, is part of the contextual framework that creates meaning. Implicit, too, within Bronfenbrenner's Bio-Ecological Theory is the idea that the number and nature of the connections made by the child could enable the construction of meaning, helping the child to cope better with the hospital situation.

The play therapist seeks to understand the phenomenal field of the child; everything that is experienced by the child. Sweeney and Landreth believe that "the best vantage point for understanding the child's behaviour is from the internal frame of reference of the child" (Sweeney and Landreth in Schaeffer (ed.), 2003, p.79). This internal frame of reference is what is perceived by a child as their reality: "The child's perception of reality is what needs to be understood if the child and the behaviours of the child are to be understood" (Sweeney and Landreth in Schaeffer (ed.), 2003, p.77).

What is understood as the self in this play therapy approach is "that differentiated aspect of the phenomenal field that develops from the child's interactions with others" (Schaeffer (ed.), 2003, p.78)<sup>130</sup>. Therefore, the perception of self in this approach can function as a reference point to how children describe themselves and how they relate to others. This confirms the importance of Bronfenbrenner's development of Bio-Ecological Theory which gives more consideration to the person as a context. This is especially important as children's perception of self may change as the condition of their health becomes more clearly understood by them.

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<sup>130</sup> This model would suggest that the healthcare chaplain using a SAT can discover through the use of an interpretative framework what meaning is generated by a child and how a patient makes connections. In identifying this, the healthcare chaplain would then be able to interpret what are the spiritual needs of a child.

Play, understood through this approach, can indicate how a child presents their view of dyads, and why such connections are significant to that child in that given context. This enables the play therapist to select the most appropriate therapeutic interventions and allows the chaplain to assess the spiritual needs of the child, using the play element of the SAT.

### **E. Play and the safety of the child**

“Children may feel less threatened and be more likely to express their true feelings in the context of play” (Santrock, 2007, p.508).

Measures must be in place to ensure a child is kept safe in the assessment setting. If children at play feel, even subconsciously, that they are in a safe environment, they may feel secure enough to share aspects of their own vulnerability. Conversely, if they do not feel safe and are therefore unable to share information, then it is difficult for the healthcare professional to know what is required to resolve this. Creating a safe environment is an aim of the SAT used in this study, but how is it to be achieved? According to Landreth:

A dynamic interpersonal relationship between a child (or person of any age) and a therapist trained in play therapy procedures who provides selected play materials and facilitates the development of a safe relationship for the child to fully express and explore self (feelings, thoughts, experiences, and behaviours) through play, the child’s natural medium of communication, for optimal growth and development (Landreth, 2002, p.16).

This description highlights two important factors associated with the use of play as a means to relate to a child. Firstly, play is understood as a natural way to communicate and relate with a child. However, if a professional taps into such an intuitive way for a child to share, the responsibility for the child’s vulnerability in this context rests with the professional as the child may be unaware of it; children make themselves voluntarily vulnerable as they share significant aspects about their life. What is the appropriate professional response to ensure a child feels safe in such a setting? Secondly, training is required to allow for the appropriate conducting of a play activity which gives the child control, but does not allow them to be out of control; the chaplain as assessor must develop a diagnostic style which invites the sort of

discussion which reveals the spirituality of the child. Chapter 8 deals with the competences required for a healthcare chaplain to conduct a SAT.

Specific features in this model of play therapy, although not necessarily transferable, illustrate the integration of theory and practice. These features are; that there is no place for directing questions to the child; and that the platform of play is the complete source of information for the therapist. The rationale is captured in this statement:

Questions tend to move children from the world of emotion into the world of cognition, which essentially defeats the developmental rationale for using play therapy. Questions also structure the relationship according to the therapist's agenda, thus placing the focus on the therapist rather than the child (Sweeney and Landreth 2003, p.81).

Whilst the use of unstructured play may be one means of gathering information about the emotional state of a child, this approach would necessarily negate the explorations required in this thesis, which take into consideration the cognitive dimension of the child and the need to gather specific verbal data from a child.

The use of questions in an assessment is a mode of gathering information which suggests some intention by those who ask the questions, albeit subconsciously. I would suggest that Sweeney and Landreth do still have an 'agenda', which is a healthy outcome based on their definition of a healthy child. However, the impact of the intervention made by the healthcare chaplain as assessor may have an impact on the child's expectations of co-operation, regardless of the absence of questions. How much of a professional's agenda is relayed to the child and perceived by them? When conducting a SAT, the agenda is to gather information. In the interviews for this thesis the children gave consent, understood the purpose of the interview and were aware that they had the option to withdraw consent at any time. It is important that the child retains a sense of control in the encounter and that questions should not interfere with their sense of being in a safe environment, the absence of which might lessen the child's ability to share.

Frances Ward describes the setting required for an interview as being:

a safe place, where the play is not constrained and is able to be spontaneous, not compliant or acquiescent. And then, in this space, the child is able to take risks and enter places which are exciting, and even precarious (Ward, 2005, p.91).

The word “precarious” in this description may be misleading, as ideas explored in a play context would only be precarious outside the bounds of pretence. However, it is necessary to ensure that children have a sense of a secure environment where they can explore aspects of their life which might indeed make them *feel* precarious. If the interviews in this study were to use picture cards representing clinical procedures which may remind children of painful interventions, this may illustrate the precarious nature of their time in hospital. When information is given to the participants prior to taking part in this study, it is made clear that if a child becomes upset at any point during the interview, the interview will be stopped. It is the responsibility of the healthcare chaplain to ensure such safeguards are in place.

## **F. Summary**

Sweeney and Landreth’s play therapy model illustrates the dynamics between theory and practice, based on the dynamics of the reasons for a child’s behaviour and how that relates to their treatment. Similarly, an assessor’s particular approach to gathering information using a SAT in a healthcare setting should be based on an understanding of the most appropriate environment and methodology to enable a child to share information. The comparison between the play therapy model and the methodology proposed for the SAT elucidates the features required and indicates possible parameters related to how play can be used in conducting the SAT. Both play therapy and SATs seek to affirm the child and their perception of how they connect to their world. But while play therapists claim to have no agenda, a healthcare chaplain using a SAT has a clear agenda; to gather information with the intention of using it to provide better care. This has an impact on the nature of the play used, and although both play therapist and chaplain aim to facilitate children’s understanding of their situation, the role of the chaplain is more interactive. The healthcare chaplain in this study is not a therapeutic facilitator but a diagnostic facilitator, and as such requires more control of the situation than the play therapist in order to achieve his goal in a short period of time. However, this does not mean that the chaplain should not engage in a therapeutic manner when gathering diagnostic information.

Play therapists often deal with traumatised and seriously troubled children with behavioural difficulties, which can affect how the child engages with the world around them. It is unlikely that children in this study will have been admitted to hospital as a result of these issues, and as such, different styles of play might suit different settings and health conditions of the more varied setting of an acute paediatric hospital. In both settings, it is clear that in order for children to become vulnerable in sharing information about their life, the healthcare chaplain must ensure that the environment remains safe and that children are supported by appropriately trained staff.

This chapter thus far has confirmed that play is a significant part of a child's life, even when in hospital. The theories and models explored have established that play is versatile, having the capacity to allow an assessor and a child to connect; but that there should be a transparency of purpose for which the play is employed. The discussion will now focus on the extent to which the use of story can fulfil a similar role, proposing that it can be used as a method to gather information about how children make sense of their surroundings during their stay in a healthcare setting.

## **G. The place of story**

### *1. Introduction*

Storytelling has the capacity to form a dyadic link between an adult and a child. I considered that this could be a design feature for the SAT used in this thesis, with story providing a way for children to tell their healthcare story. Imaginative storytelling can be used as a vehicle for children to tell their own stories, and the use of story can provide a familiar structure that children can safely fit their own narrative into. I refer to the work of Susan Engel, a developmental psychologist who explores the dynamics occurring when children become storytellers. I then examine how children's story and narrative have been used in different contexts and for particular purposes; for instance, the use of story and narrative in qualitative healthcare research to elicit information used to shape care policy to meet patient's needs. I then consider how narrative and story have been used as a means to communicate transforming truths to, and through, children in a religious context, with reference to Godly Play. These points assist in formulating thinking about the extent to which the use of storytelling may be suitable as a feature of a SAT to be used in a paediatric healthcare setting.

## 2. *Children as story tellers*

In her book *The Stories Children Tell*, Susan Engel highlights that storytelling is important to a child's development:

Every story a child tells, acts out through play or writes, contributes to a self-portrait – a portrait that he can look at, refer to, think about, and change, a portrait others can use to develop an understanding of the storyteller. . . .Each time a child describes an experience he or someone else has had, he constructs part of his past, adding to his sense of who he is conveying that sense to others (Engel, 1995, p.1).

Engel considers that the act of storytelling develops the child's awareness of who they are and how they relate to the world. As a child develops, language becomes more accessible and increases in complexity. This is reflected in their storytelling (Engel, 1995, pp.200-203) and in the structuring of the story itself, which is often event-focused and includes people, places, action and a timeframe. Woven throughout these stories are themes and meanings which can be developed through the perspective of the narrator.

Engel cites the Russian Psychologist Alexander Luria,<sup>131</sup> who refers to the presence of language as giving human beings a “double world” where there is “experience and the retelling of that experience” (Engel, 1995, p.7). Engel elaborates on this, proposing that “Children tell stories to organize their experience and their knowledge and to communicate that knowledge to others . . . But stories not only reconstruct experience and communicate experience, they are experience” (Engel, 1995, p.54). This understanding of stories as experience is significant to the use of story in this thesis. If Engel is correct, the story as an experience lets children communicate at a level where the assessor can observe how they have constructed their world and how they are affected by it: “narratives are, by their very nature, a personal and interpretive product of a constructive process” (Engel, 1995, p.99).

Such observations are not just about the development of children and their language, but about the social context in which that language is communicated and how that experience is

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<sup>131</sup> He was a famous Soviet neuropsychologist and developmental psychologist. He was one of the founders of cultural-historical psychology and psychological activity theory. (Cited on the web 10/9/12 - <http://luria.ucsd.edu/bio.html>)

retold by them. The place of stories within culture can also affect projected or imagined experience and how that is anticipated. Engel states that “language is the child’s passport into his culture” (Engel, 1995, p.46). Engel suggests that children’s successful development can depend on how adept they are at engaging with and observing their surroundings and language provides the means to do this. For the chaplain, it would be interesting to observe how well a child can use language to tell a story in relation to an unfamiliar context, such as a paediatric hospital. If the child is unable to tell a story in such a setting, this may suggest that there might be a gap in how a child can construct their experience and use it for the future. For example, if the child is unable to provide an ending because she does not know the outcome of her healthcare journey.<sup>132</sup>

However, children may be able to project how they would feel in an unfamiliar context because of past experience of storytelling within their family; whether as a result of listening to an older sibling’s experience; listening to someone in their religious community; or even hearing a story from popular culture, such as a hospital drama, which enables them to imagine how they would be in an unfamiliar context (Engel, 1995, p.10). In stressing the importance of story in the construction of the social world, Engel refers to the work of Jerome Bruner<sup>133</sup>, a psychologist, who indicates that “we learn about the social world through narrative” (Engel, 1995, p.9). Bruner identifies that a person’s narrative is an indicator of the cultural construction they use to understand and interpret their surroundings.

In this study, I examine how a child shares stories with the SAT assessor. The stories shared are social stories about an unfamiliar context other than the hospital context. For example, while in hospital a child might construct and share a narrative about what happens at home that is different to the narrative shared when at school amongst friends.<sup>134</sup> The selection of

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<sup>132</sup> While this may generate identifiable difficulties, a child who may provide an ending to their story may have a different set of needs as the ending may not correspond with what is predicted by their healthcare team.

<sup>133</sup> Jerome Bruner is an American psychologist who has contributed to cognitive psychology and cognitive learning theory in educational psychology. <http://www.psych.nyu.edu/bruner/#biography> (cited on 10/9/12) Bruner in 1991, published an article in *Critical Inquiry* entitled "The Narrative Construction of Reality." In this article, he argued that the mind structures its sense of reality using mediation through "cultural products, like language and other symbolic systems" (3). He specifically focuses on the idea of narrative as one of these cultural products".

<http://www.jstor.org/discover/10.2307/1343711?uid=3738032&uid=2&uid=4&sid=21101209461497> (cited on 10/9/12)

<sup>134</sup> How narratives are told by patients are being explored so that caring professions as understand what the implications might be (McCance, McKenna and Boore, 2001, p.351)

stories about home is significant, as the criteria used by the child may offer insight into what the child wants to share with the listener.

### *3. The projected views of children in storytelling and the narratives within*

Children not only tell stories of actual experience to build a sense of self, they also invent stories about things that might happen, that couldn't possibly happen, that they wish would happen, or that they hope fervently will never happen. . . Children weave together real concerns, real experiences, and fantasy to convey what is important to them (Engel, 1995, p.12, 13).

Story telling engages children's creativity and their ability to project views onto future possibilities and this may offer insight into their concerns, fears and hopes. In a healthcare setting, it may enable staff to understand how to prepare or support them. However, using story as a means of diagnosis is a more complex process than simply listening to a story. The listener must understand the background to the story, the choice of story and the comments within the storytelling. Examining these aspects, Engel makes a distinction between storytelling and narrative:

A narrative is an account of experiences or events that are temporally sequenced and convey some meaning. A narrative can be of an imagined event or a lived everyday event. But, unlike a story, which is told or communicated intentionally, a narrative can be embedded in a conversation or interaction and need not be experienced as a story by the speakers (Engel, 1995, p.19).

Children's stories can then, unwittingly, be vehicles for narratives which have the capacity to provide insight into their perspectives, over and above the reason they chose a particular story or the point they intended to make by telling it. This could relate to something that the child experienced in the past, either that they liked or that they wished to avoid in the future. The story itself, then, may not be the key to understanding the child, but may be understood as being the vehicle used to carry narrative fragments. Indeed, the content of the discussions

prior to the storytelling could be as significant as the story itself in providing information about the child.

Through the work of Roger Schank and Robert Abelson's Script Theory<sup>135</sup> of knowledge and through the later work of Katherine Nelson's Event Knowledge,<sup>136</sup> Engel identifies that story and narrative are a process of development characterized by the use of memory and made accessible through what Nelson calls socially meaningful units or *event sequences*. For example, asking a child "What did you do before break time?" creates a sequence of events that can easily be identified. In a healthcare setting, the paediatric patient may be able to identify certain events, such as the point of admission or a medical intervention, in order to tell and locate the sequence of their story. A child, through a hospital story, is able to access experiences and perspectives that help them to share information, thus enabling the listener to interpret how the healthcare journey has affected the child.

Engel highlights the significance of story and narrative in the life and development of the child, identifying it as a means to communication; "by reconstructing experiences in a narrative form, children put events into a coherent, meaningful order, a sequence" (Engel, 1995, p.34). This reconstruction and sequencing of experience makes it possible for a child to structure their thoughts and communicate personal information to a healthcare professional.

Engel also considers the dynamic between the storyteller and the listener; the nature of the dynamic is crucial to ensure that meaning is not lost in the storytelling process. In expanding on this dynamic, Engel refers to the Speech Act Theory developed by Barbara Rogoff. It pinpoints three aspects which affect the process of the story:<sup>137</sup> the locution (What is said), the illocution (what is meant) and the perlocution (the effect of what is said) (Engel, 1995,

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<sup>135</sup> Both of them explored how script theory identified the means of how knowledge is conveyed. They believed that there were certain ordered events where there is an expectation to receive information at a given time. This involved them in studying about artificial intelligence

<sup>136</sup> A University of New York professor who was a pioneer in infant perception and memory. The "mediated mind" is a term coined by Dr. Nelson and it refers to how cognitive development is mediated by the sociocultural context, including language and social interaction. (Cited on the web 9/11/10 - <http://www.questia.com/app/direct/SM.qst>)

<sup>137</sup> Barbara Rogoff is an educator whose interests lie in understanding and communicating the different learning thrusts between cultures, especially within her book *The Cultural Nature of Human Development* (2003). Her work bridges psychology with anthropology, drawing on Vygotsky. (cited on the web 10/9/12 - <http://people.ucsc.edu/~brogoff/>)

pp.76-77). Engel develops Rogoff's theory into a four stage process using Tzvetan Todorov's process<sup>138</sup> of:

1. The author's narrative
2. Imaginary universe evoked by the author
3. Imaginary universe constructed by the reader
4. The reader's narrative

Engel states that the four stages in the process "allow us to understand any given child's story in terms of what we think the child intended to say, what we actually put into his text, and what meanings it evoked in a listener" (Engel, 1995, p.78). This breakdown by Todorov of a child's process of telling a story helps Engel to differentiate the child's intended meaning from the listener's invested meaning<sup>139</sup> and can bring out shared or intersecting meanings between teller and listener. Engel emphasizes that it is the responsibility of the listener not to misinterpret how the emotions of the child are communicated through the narrative. The listener must ensure that they correctly interpret the narrative and convey the story told. This is explored further in Chapter 8, which addresses the professional competency of the assessor.

#### *4. The events children describe and how they construct them*

Engel indicates three types of events that children include in stories; stories of personal experience; stories that a child tells collaboratively with others; and fictional stories.

In an attempt to identify the characteristics of personal experience in children's stories, Engel conducted a study of 7 year old children who were given an autobiographical exercise to do.

Three approaches to storytelling emerged from the interviews with the children:

- conventional chronological accounts
- collections of snapshots approach with no chronology
- ordered chronological scenes to channel selected scenes

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<sup>138</sup> Tzvetan Todorov is a Franco-Bulgarian philosopher writing books and essays about literary theory, thought history and culture theory. (cited on the web 10/9/12 - <http://www.signosemio.com/todorov/index-en.asp>)

<sup>139</sup> This would be a very specific form of reflexivity in terms of listening in relation to story telling.

Engel refers to the storytelling of children as a process; she proposes five narrative developmental phases:

1. The emergence of self in the stories
2. Creating the past with parents
3. The self, shared with young friends
4. The self, constructed through many stories
5. Crystallization of the Childhood self

This framework can help to identify, through story construction, what developmental stage the child has reached. It is important that a healthcare chaplain, in the role of listener, understands the type of story a child is telling in order to accurately interpret its significance.

#### *5. Summary of Section F*

Engel's work provides an insight into the child's inner life; providing a basis for listeners to understand the meaning of the child's story and to discern information from its selection, its form, and its structure. It also provides a basis to identify narrative fragments within a story, and to interpret what a child has perceived from past experience or what is projected into the anticipated future. Engel suggests that a children's storytelling ability demonstrates an understanding of their social, emotional, and cultural dimensions and how these have shaped their sense of self. Storytelling in itself is an event and experience which has the potential to shape a child's perception of the future:

Children's stories can be vital to us as parents, teachers, and researchers because they give us insight into how children of different ages experience the world, and how a specific child thinks and feels (Engel, 1995, p.3).

The success of this methodology in these fields of inquiry, in gathering the data required, may indicate that play and storytelling are both key to enable a child to share information. I will now look at the implications of this for other fields of application.

#### **H. A selection of applications of storytelling and play**

## 1. Qualitative Healthcare Research

It has become apparent to healthcare researchers, and in particular, the nursing profession, that research amongst children is best conducted through qualitative methods, including children telling personal stories about their stay in hospital. John Swinton and Harriet Mowat describe in their book, *Practical Theology and Qualitative Research* (2006), the different types of knowledge possessed by a scientist. A scientist bases knowledge of the world on the evidence gained from experiments in the laboratory, but bases knowledge about relationships with those he loves on the experience he has of sharing his life with them (Swinton et al., 2006, p.42). It is this latter aspect of the scientist's experience which, Emily Hansen<sup>140</sup> suggests, is addressed by qualitative research when she observes that "to understand human actions and behaviours, we need to understand the meaning and interpretations that people give to their own actions, to the actions of others and to situations and events" (Hansen, 2006, p.5). Judith Green<sup>141</sup> states that:

it might be more useful to characterize qualitative research, not by the kind of data produced or the methods used to produce them, but by the overall aims of the study. Qualitative studies tend to be characterised by having aims that seek answers to questions about the 'what', 'how' or 'why' of a phenomenon, rather than questions about 'how many' or 'how much' (Green, 2004, p.5; Krahn, Hohn and Kime, 1995, p.206).

The thinking which underpins the adoption of this approach with children is described by Imelda Coyne:<sup>142</sup>

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<sup>140</sup> Emily Hansen is a Research Fellow in the Discipline of General Practice at the University of Tasmania and teaches qualitative research methods to applied health researchers. She holds a PhD in sociology and was awarded a Dean's Commendation for Outstanding Doctoral Theses. (cited on the web 16/11/10 <http://www.menzies.utas.edu.au/information.php?Doo=ViewDataandtype=PersonandID=114>)

<sup>141</sup> She is a medical sociologist responsible in developing capacity in qualitative approaches to health research for students at London School of Hygiene and Tropical Medicine, research colleagues and collaborators. (cited on the web 16/11/10 <http://www.lshtm.ac.uk/people/green.judith>)

<sup>142</sup> An Associate Professor in the School of Nursing and Midwifery, Trinity College Dublin, Ireland. Previous post include: Director of Undergraduate Studies, Director of the Diploma in Nursing at Dublin City University. She has over twenty years experience in children's nursing firstly as a practising nurse and then as a lecturer. My programme of research focuses upon: parent participation/family centred care, children's nurses contribution to care, neonatal care provision, child and adolescent mental health services, family nursing, children's participation in consultation and decision-making." (This summary was cited on the web 9/11/11 - [http://healthsciences.tcd.ie/pls/Nursing\\_Midwifery/staff.detail?uname=coynei](http://healthsciences.tcd.ie/pls/Nursing_Midwifery/staff.detail?uname=coynei))

Traditionally the adult's view of Children's perspective has been sought, with parents generally acting as proxies for children. However, this situation is rapidly changing as researchers are recognizing increasingly the importance of directly recording children's own perspectives (Coyne, 2006, p.327).

Engel implies that, in the past, children's narratives would have been considered immature and even inadequate but now "researchers have begun to identify the techniques by which children communicate the personal meaning of their stories" (Engel, 1995, p.96).

There is increasing confidence in children's capacity to report and reflect on their experiences (Boyd and Hunsberger, 1998, p.332; Forsner, 2005, p.155), although some difficulties with children's capacity to report, due to problems with methodology, have been identified (Crisp, 2005, p.70; Twycross, 2005, p.36). The diversity of approaches currently in use is evident in a study conducted by Boyd and Hunsberger, focusing on children aged between 9 and 13 years old, who were repeatedly hospitalised. Data were collected using a number of approaches including the use of artwork, semi structured interviews, and daily journals.

In my recent article "The Spiritual Needs of Hospitalized School Aged Children with Complex Healthcare Needs" (Bull and Gillies, 2007) data were collected using a technique of storytelling through sequential pictures adopted from a study led by Professor C. Ebmeier et al. in an Mid-West American Catholic Hospital in the 1990s. Ebmeier's research explored the children's view of God by using a story technique through four pictures of a child's journey through hospital. Ebmeier notes that:

in summary, research shows that 8-10 year old children are capable of having religious experiences which are affected by existing fears, fantasies, feelings of guilt and limited cognitive ability. The literature verifies that hospitalisation is a stressful situation that stimulates fears, fantasies and feelings of guilt. Hospitalised school-aged children are under stress and may turn to God for comfort or blame (Ebmeier et al., 1991, p.339).

The findings of Ebmeier's study were ascertained from data collected from children's storytelling.

What was significant in the children's use of the pictures for storytelling during my research at Yorkhill was the way children sought to make the pictures correspond more closely to their own hospital experience. This was particularly noticeable with one child who interpreted the picture of a child without family or a carer as the absence or separation from either family or friend. The child said, "He might be taken away from his family for a wee while – to be in hospital." Later, the child, making comment on the picture of the nurse administering an injection, said "Again ... there's only a nurse there, and ... there's no-one there from his family or friends to hold his hand, so he's probably feeling even more anxious" (Bull, 2007, p.36).

This child's insistence on correlating the picture to their personal experience illustrates that research in the healthcare setting has successfully embraced qualitative methods, such as listening to a child's personal stories; and that this approach has yielded valuable information to inform and shape the nature of care. If it is possible for children to construct their own stories in order to share their experience of the world, such as a hospital, is it possible that children are also able to inform adult listeners about their spirituality through storytelling? This is something that has been explored and developed in a tool called Godly play (Berryman, 2002).

## *2. Godly Play and Jerome Berryman*

### *a. An Outline*

There is a wealth of material available for religious instruction, but one particular set of teaching material was brought to my attention through its tentative use within the healthcare chaplaincy.<sup>143</sup> 'Godly Play' provided a model for me to develop my thinking concerning the

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<sup>143</sup> This happened twice in training contexts. The first was a residential conference held in Leeds when a trainer of Godly play was part of the programme. It was then featured in a College of Healthcare Chaplains (CHCC)

most appropriate way to understand the spiritual needs of children in a healthcare setting. However, prior to this project I was reluctant to use it in its published format. I was unable to articulate the reasons at the time but this project has helped me to appreciate some aspects of this model while identifying a stronger basis for rejecting other elements of it. Rather than providing a descriptive overview, the purpose of the following section is to discover the outcome of engaging with this model. This engagement has resulted in my research moving in a different direction to the direction taken by the proponents of Godly Play.

Jerome Berryman,<sup>144</sup> a healthcare chaplain based in the United States, developed a series of books for use with children, entitled 'Godly Play'. Building on the work of the Italian Hebrew Scholar Sofia Cavalletti<sup>145</sup> the books have a particular approach to the telling of Bible stories to children and were developed initially as teaching resources for the church context, through the book, *Young Children and worship* (Stewart and Berryman, 1989; Berryman, 1984 p.124).

Berryman's rationale for using a new method of storytelling to explore the Bible was that "Our thesis is that story is not a frill, not an ornament, not an illustration, not a diversion, not an entertainment and certainly not backward. Instead, it is a unique way of knowing, as valid as science though entirely different in its usefulness" (Berryman, 2002, p.21).

The format of the Godly Play books is to welcome children into a designated room, a safe place "to be with God, to talk with God, to listen to God, and to hear the stories of God" (Stewart et al., 1989, p.57). In Godly Play, the story teller tells the Bible story to children sitting in a circle. They are invited to be part of a story and the story is told in a deliberately slow manner, focussing on the objects used in the story; for example, a toy sheep from the story of the lost sheep. These, and other objects, are brought out of what is called a parable box. Once the story is finished, the story teller allows responses to be made by the listeners

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conference seminar in 2007. It was felt that those organising these events felt that its inclusion in the programme was a means for healthcare chaplains to use the material within their working context.

<sup>144</sup> Jerome W. Berryman is an Episcopal priest at Christ Church Cathedral, Houston, Texas, where he researches the function of religious language in child development. (Cited on the web 16/11/10 [http://www.reformedworship.org/about/bio.cfm?person\\_id=32](http://www.reformedworship.org/about/bio.cfm?person_id=32))

<sup>145</sup> The Talbot School of Theology website states that "Her approach to religious education relies heavily on the Montessori Method of education. Catechesis of the Good Shepherd is a three-level, nine-year approach to religious education that aims to help children to have "a living encounter with the living God." (Cited on 26/6/12 in - [http://www2.talbot.edu/ce20/educators/view.cfm?n=sophia\\_cavaletti](http://www2.talbot.edu/ce20/educators/view.cfm?n=sophia_cavaletti) . Further information on the Montessori Method can be located on <http://www.montessorisociety.org.uk/> (Cited 26/6/12)

and “she never calls one answer good or another answer wrong. She simply listens and accepts the responses” (Berryman, 2002, p.16).

Berryman calls this process a “holy reading” where a story is recounted, reflected on, and facilitated by a series of questions such as, “I wonder where you are in the story or what part of the story is about you?” This approach goes beyond conveying biblical facts as an age-appropriate accessible means of communication, and has the capacity to address and deliver a spiritual experience through the storyteller, allowing the children to be part of that spiritual formation.

However, Berryman’s approach raises questions, such as “Is this tool which has been developed within a religious community transferable to another context?” It appears that Berryman expects all those involved to share their story from the heart, and allow the child to tell the bible story. This is an individualistic, internalised process which becomes transparent only to the listener who places trust in the storyteller. While this approach may add to the drama and assist people to have a sense of connection in the story, it may not be appropriate in other contexts. It is useful to identify the issues which might emerge in these other contexts, and to identify the relevance of Berryman’s approach in shaping an appropriate methodology for use in a paediatric healthcare setting. Berryman’s approach has received acceptance in different strands of the church<sup>146</sup> and allows for a new format of instruction of ancient religious themes. However, this does not test the appropriateness of the model of Godly Play for use with children in a hospital setting. I would suggest that using story as a means to relate to children is a positive move, but that further changes are necessary: the child, not the adult, must be the storyteller and the content of the stories must be changed to reflect the child’s healthcare journey.

*b. The significance between the context and the storyteller – A school governor’s handling of Godly Play in the educational setting*

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<sup>146</sup> Catherine Stonehouse is Orlean Bullard Beeson Professor of Christian Education at Asbury Theological Seminary, Wilmore, Kentucky (cited on the web 16/11/10 <http://www.asburyseminary.edu/faculty/dr-catherine-stonehouse>) She explains about Godly play in the article, “After a child’s first dance with God: Accompanying Children on a Protestant Spiritual Journey,” (Yust, Johnson, Sasso and Roehlkepartain, 2005, p.95) This is from a Wesleyan Protestantism perspective and is commonly known as Methodism. It is a Christian denomination that emerged in 1828 from the Anglican Church through John and Charles Wesley.

Concern has been expressed about the place of religious education within the English Education system,<sup>147</sup> and although this is not the concern of this thesis, Garland's argument as to how to overcome the problematic place of religious education by using Godly Play, is useful in illustrating the potential problems of using story to achieve this (Garland, 2007). "Forming the spirit of the child" is the main concern of Garland's article, "Receiving the Kingdom, in the contemporary contest over religious education what place is there for Godly Play?" His article is based on his belief that the complete development of the child depends on the use of story, and the focus of the story on ancient religious themes. The events of the story told are as significant as the story itself. It is the storyteller's discovery that is crucial in this process. The problem with Garland's handling of Godly Play in an educational context is illustrated when he says that:

What takes place in Godly Play is not absorption within the horizon of the subject but a fusion of horizons between child and story, so that the child becomes a participant in a living tradition (Garland, 2007, p.29).

Is this fusion with a living tradition an appropriate educational outcome for a child? Whatever the answer might be for the educational context,<sup>148</sup> in the healthcare context this combination would only create confusion. What is of interest is that Garland feels that the educational curriculum is not broad enough and that Godly Play affords that breadth.<sup>149</sup> The use of story allows a meaningful methodology for discovery of the child's own understanding; whether that is of themselves or of themselves in relation to the story told.

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<sup>147</sup> See also Christopher Clouder article (1998)

<sup>148</sup> Garland is resistant to the views of David Hay who considers religious knowledge, "irrelevant to a spiritual education that focuses upon the health and well-being of a child" (Garland, 2007, p.9). Hay is influenced by William James, an American pragmatist, – "In his Gifford Lectures at the University of Edinburgh he provided a wide-ranging account of *The Varieties of Religious Experience* (1902) (cited on the web 10/9/12 [http://www.worldu.edu/library/william\\_james\\_var.pdf](http://www.worldu.edu/library/william_james_var.pdf))

<sup>149</sup> Garland, who seeks support from Stanley Hauerwas considers the removal of the religious dimension to be unhelpful, in particular when there is an assumption that intrinsic spirituality is unaffected by any other influences in the cultural context of a child, and that "child-centredness is an unmitigated good." (Garland, 2007, p.11) The criticism he raises, through Stanley Hauerwas, is that "James' pragmatism restricts itself to a narrow view of knowledge, one essentially restricted to what can be empirically observed." (Garland, 2007, p.9) This approach would expose the child to, "the risk of separating spirituality and religion, introducing a child to a way of using language and culture based on a subjective, romantic notion of experience combined with a narrow, objective act of choice." (Garland, 2007, p.9)

Stanley Hauerwas – Gilbert T. Rowe Professor of Theological Ethics at Duke Divinity School with a joint appointment at the Duke University School of Law (cited on the web 10/9/12 - <http://stanleyhauerwas.blogspot.co.uk/p/bio.html>)

As Garland's interest is in education, it is understandable that the focus is on communication *towards* the child; within the healthcare setting the emphasis is rather on communication *from* the child which underlines the need for the child to tell their own story in order to discover who they are as a person in a specific context. This approach involves a move away from the rationale behind the model of Godly Play. However, it does not dispense with the intentional selection of material for the storyteller; there is a need for fusion between the paediatric patient as storyteller and the healthcare setting. For this study, the story should be set in the hospital so that the healthcare chaplain hears the story of the child's healthcare journey from the child's perspective. If the healthcare chaplain listens to the storyteller, there needs to be an understanding of how a child's story is constructed, in order for the chaplain to interpret what is portrayed and consider the child's projections about the future. Using a hospital based story in the SAT would be an intentional measure to find out information about the child in relation to their healthcare journey, whilst giving children the freedom to tell their story from within that context. They will then be able to inform that story with the stories they already own and use to interpret their experience. The healthcare chaplain must be aware of the types of story a child might draw upon and must avoid being prejudiced against them.

## **I. Summary of the Chapter**

The preceding discussion has highlighted that the use of play can create an environment where a child feels more able to engage and share, and that the use of story can facilitate communication appropriate to the developmental stage the child is at. In addition, it has been affirmed that at a theoretical and practical level, play and story are significant and justifiable design techniques for inclusion in the SAT portfolio in order to gain understanding of paediatric patients in a healthcare setting. The word "affirm" is deliberately selected as it reflects the process of this research. I am of the opinion that play and story are integral to the ability to successfully relate to children and through reading and conducting interviews, this approach has been refined and focused to be applied appropriately, be fit for purpose and considered as a justifiable basis for working with and relating to children. However, before this approach is considered, Chapter 4 will explore how other approaches have been adopted and applied to gather information to establish a spiritual assessment of patients.



## Chapter 4 Spiritual Assessment Tools: the struggle to offer help

It is increasingly recognized that healthcare professionals should consider conducting a spiritual assessment as part of the holistic service provision (Hodge, 2005, p.314).

### A. Introduction

Chapters 2 and 3 identified appropriate approaches to understanding and relating to children. Specific features were identified that offer insight into understanding how children's spirituality may be presented in terms of their stage of development and also their ecology. In addition to this, the development of a conceptual framework for interpreting childhood spirituality is intended to help an assessor understand how and why to relate to a child. If this new perspective is to be applied in the healthcare context, it is useful to consider what current practices are in this area. In order to develop a better understanding of children in the healthcare context, this thesis will focus on assessment as a specific part of the overall healthcare process (Mowat, 2008, p.61). This allows for close attention to be paid to the details of what is involved in this one aspect of the complex and long process of providing paediatric healthcare. The first step in developing a framework for a SAT is to provide a preliminary outline of the cultural and professional rationale for the use of a SAT in a healthcare setting.<sup>150</sup> This then provides context for the overview of SATs which are already in existence. Such an overview cannot be exhaustive as the purpose here is to highlight the main characteristics of these SATs, and to devise a categorisation which offers insight into design features that may correlate with an appropriate method of assessing children in hospital.

In order to limit the list of SATs reviewed, the following discussion will draw from the work of David R. Hodge,<sup>151</sup> a social worker who has reviewed SATs so that the right tool may be applied in order to meet patient needs. Hodge's work is selected as the main source from

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<sup>150</sup> This professional response reflects the dynamics of the social map of healthcare chaplains as described by Cobb. Assessment of any form in the hospital community is a crucial process so that the appropriate care and treatment can be offered. Healthcare chaplains also need to offer appropriate care and to identify the spiritual needs of patient has been addressed by healthcare chaplains by the introduction of a spiritual assessment tool. One factor that relates to the previous chapter is that the formalisation of spiritual assessment tools as part of the official multidisciplinary team's care plan, in my view, relates to the recognition of a healthcare chaplain whether that be through national professional recognition or by the nature of the institution that employs them such as a hospice. When this is not in place, then healthcare chaplains have developed their own means of spiritual assessment to act professionally. This has resulted in a plethora of spiritual assessment tools.

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which to distil the essence of a plethora of SATs for two reasons. Firstly, unlike the proliferation of publications from other professionals describing SATs, Hodge moves beyond a proposal for assessment to a proposal for good practice by reviewing the inappropriate use of SATs by undiscerning peers. Secondly, his overview allows for more effective categorisation of SATs based on their type and provides insight into the purpose and style of SATs; highlighting the benefits for the patient and assessor, and indicating potential limitations.<sup>152</sup> He also explores how to understand the individual in relation to the context of care, with discussion focusing on the process and rationale of assessment. Other writers tend to focus more on the care provided, and pay too little attention to the patient, or conversely so much attention that not enough is given to what care may be required in a particular context. To complement this, I have also considered a Canadian study conducted by O'Connor, O'Neill, Van Staaldin, Meakes, Penner, and Davis (2005) which offers possible reasons for the significant under use of SATs by healthcare chaplains.

The principles identified in Chapters 2 and 3 are used as a means to critique the overview of the literature on SATs presented here. The principles focus on the extent to which the SATs consider the age and stage of children, whether they engage appropriately for children and whether they account for the context of children in healthcare. In order to do this a secure zone needs to be created for them to feel able to share. The critique of the literature on SATs allows for an appreciation of how design features result in SATs that are applied inappropriately, or SATs that are insufficient. The recommendations which arise from the principles identified in Chapters 2 and 3 are that:

- in order for children to engage with a method of assessment, that method must be consistent with their stage of cognitive development
- in order for children to have a sense of purpose, the method of assessment should be relevant to their “ultimate concern” or a “joint activity dyad”
- in order for children to feel that they are in a safe environment, the assessor must take on a protective role
- in order for children to feel that the assessment focuses on their healthcare journey, the assessor should adopt a liminal role

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<sup>152</sup> McSherry and Ross which explores and develops how healthcare could incorporate spiritual assessment as part of its delivery of care. Stirling’s review sums up what he considers to be (McSherry’s) best point that a SAT, “should be safe, adaptable, easy to administer, non-intrusive and inclusive.” (Stirling, 2010, p.51).

- in order for children to explore a possibly unfamiliar setting, the assessor should take on a guiding role
- in order for children to engage openly, the assessor must use a method of assessment consistent with a child's molar activity, termed a "proximal process"

It is useful to consider the extent to which features in existing SATs may be related to the elements of play and storytelling which I propose to use in this study, and how these existing features might fall short of what is needed in relating effectively to children. In considering this, I will argue that any SAT which evolves from this study can only be fit for purpose if it relates to the development and context of paediatric patients as described in this thesis. If this is achieved, it will provide a means to further explore the extent to which this approach is suitable for gathering data in a clear and cohesive way that reflects the design of a new construct; cementing together the building blocks of the new construct and providing a new understanding of childhood spirituality and how to relate to it.

## **B. Step 1 Outline: The Purpose of a Spiritual Assessment Tool for Healthcare Professionals**

Spiritual assessment is part of spiritual care (O'Connor et al., 2005, p.97).

In essence, a SAT is one means for a healthcare professional to gather information from a patient and share it with the multidisciplinary team. The reason for gathering information is to be in a position to provide more appropriate care for a patient.<sup>153</sup> Hodge provides a rudimentary description of assessment:

Assessment is defined as the process of gathering, analyzing, and synthesizing salient data into a multi-dimensional formulation that provides the basis for action (Hodge, 2001, p.207).<sup>154</sup>

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<sup>153</sup> At one level, healthcare chaplaincy is conforming to the culture of the hospital community of ensuring their services are meeting the needs of the patient. The question is can this be achieved in terms of spiritual care? This was discussed by VandeCreek and Smith who identified a need to research the salient information a chaplain would require to make an assessment (1992, p.52)

<sup>154</sup> See also McManus; (2006), p.27

In the United States (US), there is a more established professional environment for healthcare staff to engage with religion and spirituality, meaning that governing bodies provide a mandate to address a person's spirituality within caring institutions. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), an organization which accredits most hospitals in the US, "now recommends that a spiritual assessment be conducted" (Hodge, 2005, p.314). Prior to the document being reviewed in 2008<sup>155</sup>, the stated minimum requirement for a spiritual assessment was to ask a patient about their "denomination" and "important spiritual beliefs and practices" (JCAHO, n.d.). This was complemented by a series of questions aimed at establishing this information, for instance "what type of religious/spiritual support does the patient require?" For Hodge, the requirements set out by JCAHO have a two-fold purpose "to identify the effect of client's spirituality on service provision and client care" and "to identify whether an additional, more comprehensive spiritual assessment is required" (Hodge, 2005, pp.314-315). While JCAHO do not stipulate

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<sup>155</sup> In the JCAHO website, a guide is provided by what level of SAT is required in a Question answer format as outlined below. This was cited on 26/6/12 - [http://www.jointcommission.org/standards\\_information/jcfaqdetails.aspx?StandardsFaqId=290andProgramId=1](http://www.jointcommission.org/standards_information/jcfaqdetails.aspx?StandardsFaqId=290andProgramId=1)

**Q: Does the Joint Commission specify what needs to be included in a spiritual assessment?**

A: No. Your organization would define the content and scope of spiritual and other assessments and the qualifications of the individual(s) performing the assessment.

Examples of elements that could be but are not required in a spiritual assessment include the following questions directed to the patient or his/her family:

- Who or what provides the patient with strength and hope?
- Does the patient use prayer in their life?
- How does the patient express their spirituality?
- How would the patient describe their philosophy of life?
- What type of spiritual/religious support does the patient desire?
- What is the name of the patient's clergy, ministers, chaplains, pastor, rabbi?
- What does suffering mean to the patient?
- What does dying mean to the patient?
- What are the patient's spiritual goals?
- Is there a role of church/synagogue in the patient's life?
- How does your faith help the patient cope with illness?
- How does the patient keep going day after day?
- What helps the patient get through this health care experience?
- How has illness affected the patient and his/her family?

the criteria for further assessment, Hodge suggests that such points of assessment could take place, “when the norms of the client’s faith tradition relate to the service provision and client care” and “when spirituality plays a central role, functioning as an organizing principle, in the client’s life” (Hodge, 2005, p.315).

JCAHO is not the only organisation that sets out guidelines and standards for spiritual assessment in healthcare systems. In certain healthcare contexts, such as palliative care (Mitchell, 2006, p.37) the World Health Organisation (WHO) also stipulates forms of assessment:

Spiritual care should include assessment of spirituality and the provision of appropriate spiritual help and support; a process that is underpinned by attentive listening and respect for individual beliefs (White<sup>156</sup>, 2006, p.117).

Several of the healthcare professions are responding to this global and national momentum and are engaging in the discussion about the use of spiritual assessment tools in nursing (Narayanasamy, 2004), medicine (Puchalski, Ferrell, Virani, Otis-Green, Baird, Bull, Chochinov, Handzo, Neslon-Becker, Prince-Paul, Pugliese, Sulmasy, 2009), psychiatry (D’Souza, 2003; Houskamp, Fisher and Stuber, 2004, p.228), social work (Hodge, 2006) and chaplaincy (Cobb, 2005). In this overview, I have observed that when each of these professions engages with the practice of using a SAT, the form of the tool is affected by five factors: the type of information being gathered; the framework being used to process that information; who is assessing; who is being assessed; and what they are being assessed for.

It is useful, here to refer to David Hodge, who has been a major force in crystallizing thinking about models for SATs since social workers took the initiative to decide on and create the SATs used in their professional context. Hodge examined different SAT approaches from various professional settings and his analysis provided a model of categorization for SATs which allows existing SATs, outside of Hodge’s review, to be incorporated into the classification of types listed below. The classification illustrates the possibility of tailoring a

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<sup>156</sup> Acting Clinical Director of dietetics and nutrition at Nottingham City Hospital (21/9/10)

range of SATs for use in the particular situations where spiritual assessment is required in social care.

Hodge focused on SATs during a transition phase in the social care profession which engendered a creative and entrepreneurial approach amongst his peers; providing helpful information on SATs which are actually in use and not necessarily documented in journals. Hodge asserts that a plethora of spiritual assessment tools have been produced, but that they have been adopted in a haphazard fashion, resulting in a mismatch between the needs of the patient and the information a particular tool can identify (Hodge, 2005, p.315). Hodge's review offers more than a description of each tool and also shows how it may relate to a patient. He identifies five categories which gained currency amongst his peers: spiritual history, spiritual life maps, spiritual genograms, spiritual ecomaps, and spiritual ecograms.

### **C. Step 2: An overview of the Categories of Spiritual Assessment Tools**

#### *1. Spiritual History*

Spiritual History is a type of SAT that focuses on service provision, and that is characterised by a structured, but open-ended, series of categorized questions asked by a professional during a patient's healthcare journey. This type of SAT was pioneered by Stoll in 1979, when his framework for a Spiritual History covered four areas of a person's life; their concept of the deity; their source of strength and hope; the significance of religious practices; and the relationship between spiritual and religious beliefs and health (cited by Highfield, 1997, p.237; Fawcett and Noble 2004, p.267).

One popular format of Spiritual History assessment tools is the Mnemonic Tool, consisting of a group of easily accessible questions to be asked by the healthcare professional to the patient. There are several tools published using such mnemonics as B.E.L.I.E.F. (McEvoy, 2000a, p.217; McEvoy, 2000b, p.40), B.A.T.H.E. (Stuart and Lieberman, 1999), F.I.C.A. (Pulkalski, 2000)<sup>157</sup>, S.P.I.R.I.T (Maugans, 1996; Larson, 2003, p.370), and H.O.P.E. (Anandarajah and Hight, 2001)<sup>158</sup> (Dameron, 2005, p.16). All are designed to catalogue

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<sup>157</sup> Some of these assessments are led by medical staff and are referred to as spiritual screening (Lawrence, 2004, p.152)

<sup>158</sup>B.E.L.I.E.F. represents Belief system, Ethics, Lifestyle, Involvement in spiritual community, Education, Future events

B.A.T.H.E. is an acronym for Background, Affect, Trouble, Handling, and Empathy

F.I.C.A. stands for F - Faith, Belief, Meaning, I - Importance and Influence, C - Community, A - Address / Action in Care

information about patient so that the patient's Spiritual History helps to shape the services that will best serve them (Elkins and Cavendish, 2004, p.181).

Other forms of this model have been designed to place more emphasis on the spiritual dimension of the patient rather than on service provision. One model promoted by Farran Fitchett, Quiring-Emblem, and Burck (1989), entitled the 7 x 7 Model for Spiritual Assessment, provides an interactive structure between the theoretical understanding of the spiritual dimension which includes philosophy, theology, physiology, psychology and sociology. This is used in conjunction with the practical understanding of the spiritual dimension which includes sections entitled belief and meaning, authority and guidance, experience and emotion, fellowship, ritual and practice, courage and growth, vocation and consequences. While this model is thorough, it is complicated. It is presented in a way which addresses the main principles, providing a rationale for the profile of the patient, but the research presents little and insufficient detail of how it has been used and applied in order to appreciate what this may be like in practice.<sup>159</sup>

Hodge prefers a more client-focused and less complicated model, with the structure of the questions being based on a very specific theological interpretation (Hodge, 2005, p.316). It is a verbally-orientated assessment tool which contains two sets of questions. First, there is an initial narrative framework of questions which provides practitioners with tools to assist clients to tell their stories, with questions typically moving from a focus on childhood to a focus on adulthood. Secondly, there are interpretive anthropological framework questions which elicit spiritual information as clients relate their stories.

Hodge bases these frameworks on Watchman Nee's trichotomy<sup>160</sup> of the Christian doctrine of humanity. The human being is viewed in three constitutional parts; body, soul and spirit. On the basis of this perspective, Hodge has constructed his framework to understand the human being by asserting that:

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S.P.I.R.I.T. stands for S – Spiritual belief system: P – Personal spirituality: I – Integration with a spiritual community: R – Ritualized practices and Restrictions: I – Implications for medical practice: T – Terminal events planning:

H.O.P.E stands for H – Sources of hope, meaning, comfort, strength, peace, love and connection, O- Organised Religion, P - Personal spirituality and practices, E – Effects on medical care and end of life issues

<sup>159</sup> This also reflects Peterman, Fitchett, Brady, Hernandez, and Cella, (2002) This is observed in the Appendix in p.58

<sup>160</sup> This is a particular Christian view that describes the spiritual make up of a human being comprising of a body, soul and spirit. This is based on a differentiation made between the New Testament Greek words using different words for soul and spirit. This has led Christians to disagree whether these two words describe either one ontological existence or two distinct ontological dimensions to the human being.

The anthropological derived questions are designed to elicit information about each of the six dimensions, providing a holistic spiritual assessment (Hodge, 2005, p.316).

The six dimensions referred to relate to the elements in the three dimensions of personality; affect, will and cognition, and the elements in the three dimensions of the spirit; communion, conscience and intuition. While there is strength in having a framework for human spirituality that enables the practitioner to understand the significance of the client's story, Hodge's framework cannot be universally adopted. The use of a very specific Christian doctrine is not transferable to other contexts. However, Hodge's process demonstrates that an interpretative framework can structure an assessment and the cataloguing of information. This principle and process could be used if a more general and inclusive framework was to be developed.

## *2. Spiritual Life Maps*

The Spiritual Life Map involves the creation of a diagrammatic alternative to a spiritual history and is what Hodge describes as "a pictorial delineation of a client's spiritual journey" (Hodge, 2005, p.316). The procedure of the spiritual life map assessment is to develop a sequential symbolic collage on a large sheet, which has a pre-drawn pathway of life events and spiritual resources:

The pictorial life map affords practitioners the opportunity to learn more about the client's world-view, while focusing on building therapeutic rapport by providing an atmosphere that is accepting, non-judgmental and supportive during assessment. By placing a client structured media at the center of assessment, the message is implicitly communicated that the client is a competent, proactive, self-directed, and fully engaged participant in the therapeutic process (Hodge, 2005, p.317).

Although the structure of information is not significantly different from that collected by the spiritual history approach, the process by which it is gathered differs. It introduces a neutral point of focus which exists outside of the dialogue between the professional and the patient. It

empowers the patient to take ownership as they are able to hold the SAT on a sheet of paper and write on it, rather than this being done by the assessor.<sup>161</sup>

### *3. Spiritual Genograms*

This model involves the creation of a graphic representation of the client's relationships across at least three generations. In its basic format it is a modified family tree with symbols drawn from a recognised code that is consistent with standard genogram conventions.<sup>162</sup> These symbols depict the significance of the client's relationships, special events and influential traditions or changing belief. Different members in the family can be connected by different styles of lines. A zigzag line, for example, might be used to indicate a strained relationship and a straight solid line to indicate a stable relationship. The design of this model is more focused on the influences of the past. Hodge indicates that its strengths lie in identifying how the family systems, origins, traditions and culture play a role in the client's life (Hodge, 2001b, p.46). This contextual infrastructure can help the assessor understand the aspects of life that have had a bearing on the assessed person. The assessor is then able to appreciate the needs of the patient better, as they have more understanding of what relationships and events may have contributed to the need for help (Tanyi, 2006, p.290; Moncher and Josephson, 2004, p.57).

### *4. Spiritual Ecomaps*

Genograms focus on the past, and ecomaps focus more on the present; "Spiritual ecomaps focus on the portion of a client's spiritual story that exists in present space" (Hodge, 2005, p.320). The process of creating a spiritual ecomap may involve the use of circles to depict an individual, a family system or a faith community, and these circles may be joined by a line; for example, family members may also be part of a patient's faith community. This connecting line can assist the assessor to understand how patients make connections between different areas of their lives. Hodge considers this model as being easy to construct and more immediate to the present needs of the client. Once again, the visual process allows the client

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<sup>161</sup> This dynamic begins to illustrate that the method of gathering information introduces a different dynamic that has implications on the nature of the information gathered. It offers that safe space for both the patient and the professional to enter and so agree on what is discussed and shared.

<sup>162</sup> Hodge provides this information through his on-line article - Conducting spiritual assessments: An overview of a complementary family of assessment instruments cited 26/6/12 - <http://www.stu.ca/~spirituality/HodgespiritualassessmentV18-9-06.pdf>

or patient to be actively involved in compiling the information, and reduces the intensity of any direct dialogue between the professional and the client or patient<sup>163</sup>.

### *5. Spiritual Ecograms*

Hodge states that “Spiritual ecograms combine the assessment strengths of spiritual ecomaps and genograms in a single assessment approach” (Hodge, 2005, p.321). The construction of a spiritual ecogram involves a diagrammatic process that presents the top half of the assessment as a family tree bringing together historical dimensions, while the bottom half, in connecting circles, describes the current dimensions of the patient’s life (an example can be found in Hodge, 2005b, p.291). Hodge identifies the single graphic diagram that connects the current and historical dimensions to the patient, as being a key strength of this approach. However, due to the large amount of data gathered, this combination can be time consuming and possibly too complex for its purpose.

## **D. Step 2: An overview of the common features of Spiritual Assessment Tools**

All of these models have common features that provide insight into how an assessment is affected by a social or healthcare setting. I chose to focus on these SATs, as opposed to other assessments used in academic research projects,<sup>164</sup> as they are considered to be fit for purpose in the professional work place and relate to the delivery of service by a professional in order to meet the needs of the patient. As such, these features bring together factors that need to be considered in a SAT to be used in a healthcare setting.

### *1. The purpose of an assessment: Diagnostic vs. Therapeutic*

Hodge’s analysis of SATs was designed to provide guidance to social workers in selecting the SAT most suited to the diverse needs of clients. SATs are an integral part of social work in America and all the SATS presented by Hodge were shaped for that profession and the nature of the encounter.<sup>165</sup> The need presented by the patient, and the type of service designed to meet that need, play a significant part in defining an individual’s spirituality and

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<sup>163</sup> The visual dimension in art therapy has a similar outcome when the patient is empowered to express their feelings or their situation, (Hays and Lyons, 1981, p.215), this is also the case in nursing (Johnson, 1990, p.11) Kandinsky considered this as a new form of reconstruction of meaning by those who participate in art (1977, p.57). Rollins uses this as a communication tool for children with cancer (2005, p.215) It is also recommended by Smallman for consulting children (2005).

<sup>165</sup> This is different from the procedures and delivery of service

in determining how that relates to the support of social services provided. SATs have also been devised to suit the counselling setting. Rebecca Powell Stanard<sup>166</sup> et al. state that:

the role of spiritual assessment in counselling may be viewed from two different but complementary viewpoints. From the counsellor's point of view, spiritual assessment is useful in diagnosis and treatment planning. Using the various assessment methods, counsellors can come to understand the spiritual worldviews of their clients and the potential impact of those views on issues that brings clients to counselling. From the client's viewpoint, assessment results are useful in self-exploration, self-understanding, and a perspective shift necessary for decision making and action planning (Stanard, Sandhu and Painter (1998) p.205).

Stanard's description reveals that SATs can have a therapeutic element which can play a part in the relationship between professional and patient. The design of a SAT can be shaped by a therapeutic process to help the patient benefit from increased self-awareness. For example, the SAT may enable patients who are confused by their chaotic lives to understand why it is disruptive or distressing, and they may feel better equipped to address this by having a clearer overview of their life. This, Stanard suggests, is not incidental but quite deliberate. She refers to some leading thinkers in her profession (Richard<sup>167</sup> and Bergin<sup>168</sup>, 2000), who offer five reasons for including spiritual assessment in therapeutic protocols:

1. to obtain a better understanding of the client's world views
2. to determine whether a religious orientation is healthy or unhealthy
3. to discover if a client's community is a source of help
4. to ascertaining which spiritual interventions are helpful (further details in Carey, Cobb, Equeall, 2005, p.17; Carey, 2002, p.74)
5. to determine how a client's problems are related to spiritual issues.

This approach appeals to Stanard as it has a therapeutic framework embedded within an intrinsic value system, providing reasons for undertaking an assessment. This may be

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<sup>167</sup> Associate professor in the Department of Counselling and Special Education at Brigham Young University

<sup>168</sup> He is a clinical psychologist who has a proponent of theistic values

valuable within the field of counselling, but inappropriate in other contexts as a therapeutic remit to address a spiritual need is not always the primary reason for an encounter with a healthcare professional. There may be a therapeutic outcome, but this will be incidental to the intended purpose of a visit which has a diagnostic goal as its primary concern. Patients in a healthcare context may have multiple needs, but may present with only one of those needs. They may wish only one aspect of their life to be addressed; not associate a particular need with their condition; or be unaware of that need. A diagnostic SAT allows people who are being assessed to come, in their own time, to understand that such assessment could lead to therapeutic support if they so wished. There should be no presumption, paternalism or judgment. The SAT should provide information that informs both the professional and the patient of the implications of the patient's stay and the provision required to offer an appropriate professional service. For example, in-patients may, in a time of illness, more thoughtfully reassess, through a SAT, the state of their relationships in the community. If staff are aware of patient preferences relating to visitors then this can be supported.

## *2. Context: single episode in an acute setting vs. series of appointments in a counselling setting*

The context and nature of contact between the professional and the patient can affect the design of a SAT. The therapeutic dimension described above assumes a well-defined, stable, pastoral relationship with a therapeutic outcome. This can be reinforced by the occurrence of regular appointments with the assessor. However, this may not occur in healthcare settings where the patient environment is neither stable nor as long term.<sup>169</sup> Hodge highlights this issue saying that “assessment is critical to the incorporation of strengths into the therapeutic milieu” (Hodge, 2001, p.207). In the social work setting there may be an allocated key worker who has responsibility for a patient or family over a long period of time, and so the professional role allows, even expects, the spiritual assessment tool to include a therapeutic purpose. Hodge states what that therapeutic outcome might be that:

assessment helps to provide effective, culturally sensitive services while concurrently providing a forum to explore spiritual strengths that might be used to ameliorate problems or cope with difficulties (Hodge, 2005, p.314).

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<sup>169</sup> The average stay of a child in an acute paediatric setting such as Yorkhill Hospital is 3 – 4 days

This indicates that a SAT can be shaped by the nature and length of the relationship between the professional and the patient, suggesting that the more established and stable this relationship, the more it can be conducive to a therapeutic element.

We can see from the American social work and counselling context that the repeated use of a SAT with the same person can provide information for a therapeutic outcome. This element appears to be possible due to the long-term relationships these professions can build with clients; and due to the person administering the SAT also being the provider of care, using the information gained for therapeutic purposes.

In contrast, if a SAT is used only once, or not by the same assessor, the therapeutic outcome would be limited, but the possibility of a diagnostic window into the immediate context of the patient would remain. The SAT interviews may subsequently lead to therapy, as this thesis proposes that there is spiritual need to be discovered in a paediatric setting. Further investigation and research would be required to address the therapeutic intervention appropriate for the spiritual care of a hospitalised child.

### *3. The balance of power between the patient and the professional during an assessment*

The SATs reviewed by Hodge are both used and designed by a professional, and this contributes to how the balance of power is experienced by the professional and the patient. In Chapter 8 further consideration is given to the professional's awareness of how their role might affect the balance of power and how that, in turn, might affect a patient's willingness to share information freely. However, the focus in this chapter is on the design of the tool and how that relates to the use of the tool in relation to the encounter between professional and patient.

Hodge suggests that the provision of a visual dimension in a SAT may enable a patient to feel more involved. As the visual development can be directed by the patient, the patient feels empowered to be the main driver in the encounter, with the practitioner being an observer in the process. Hodge suggests that this style of SAT distracts people from feeling self-conscious in sharing and encourages them to be more open. This approach would reduce the risk of an untrained practitioner interfering with a patient's sense of meaning by introducing his own personal philosophy. Conversely, Hodge points out that a practitioner may feel disempowered as the visual process may become client-directed. The visual representations

may also have multiple meanings, and the professional and patient may differ in their interpretations of them. In addition, the SAT would be carried out at a pace to suit the patient and this may result in it becoming a more time-consuming exercise. If a professional does not appreciate the significance of their observational role, then a disproportionate amount of time may be given to this compared to other tasks. As a result, the professional could feel disempowered to the point where it affects the way they relate to the patient. A fine balance is required to generate an encounter between patient and professional where both are engaged in a way that produces a good diagnostic outcome. In addition, the environment should encourage a flow of information. It is important that a healthcare professional appreciates the significance of his interpretative role in ensuring that the visual symbols selected by a patient are clearly understood.

*4. The focus of the information in an assessment; is it to be contextualized by the patient or by the service provided for the patient?*

Most of the SATs reviewed above are partly patient-centred and service-centred; there is a concern to understand the needs of the patient and professionals also want to be informed about how the services provided affect the patient. Some SATs focus on the needs of the healthcare service to a point where the patient seems incidental and the *process* of care is the primary concern. However, this is not to suggest that increased focus on the patient is necessarily better. Too much focus on individuals may be both exhausting and intrusive to the patient, with more information being gathered than is necessary. A balance between the needs of the patient and the needs of the service must be maintained to ensure that a patient's spiritual needs are identified; whilst the service should be sufficiently informed to deliver appropriate spiritual care. A central feature of good practice is that the professional must be clear as to the purpose of using a particular SAT in any given situation. If the aim is to help the patient to have a better hospital stay, then this must be reflected in the format of the SAT; it must account for a patient's needs being affected by the immediate environment and not only the condition which led to hospitalisation. For instance, a patient can become distressed when in close proximity to other patients who are very unwell or in discomfort.

So far, this overview has not addressed the procedural dimension which addresses the changeable context of the patient in relation to the delivery of a patient service.<sup>170</sup> This procedural dimension is identified by Martha Highfield<sup>171</sup> who has proposed a P-L-A-N assessment which is framed by the professional service. In this mnemonic, P stands for “permission”; when the caregiver gives the patient an opening to discuss spiritual concerns. L is for “Limited Information” and indicates that a patient’s limited information is in response to specific spiritual and religious questions presented to them<sup>172</sup>. A is for “activating resources”, where the caregiver assists the patient to identify and use persons and/or activities that would help them to cope. N is for “Non-nursing referral”, when a non-nursing human resource is involved in collaborative diagnosis and treatment of spiritual concerns (Highfield, 1997, p.238). This assessment model is shaped by the healthcare journey of the patient, which gives direction to the dialogue, so that the caregiver can ask questions and listen actively.

#### **D. Exploring the perceived limitations of existing Spiritual Assessment Tools**

Hodge’s overview of SATs is set in a cultural and professional context that is different from the context for healthcare chaplaincy in the UK.<sup>173</sup> In terms of SAT design this is not problematic as the aim is to highlight the complexities within the design of the tool, without being distracted by wider issues. The focus is on the functioning of the tools and not on the wider process of raising spirituality with a patient. Hodge’s review demonstrates that there are potential design difficulties related to inappropriate application, which may be reduced but not eradicated. He suggests that choosing the SAT most suitable for a particular situation is important to assist in meeting the needs of the patient and providing the techniques required by the professional to fulfil a caring remit.

Wider cultural issues cannot be ignored and it is for this reason that other sources will be examined. Hodge works in an environment in the US where a large measure of agreement exists over the definition of spiritual care. This differs from the European context where there is much less consensus. SATs are an accepted means of delivering care in the social work profession and the key issue for Hodge was to identify and promote best practice. As Europe

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<sup>170</sup> The reason why this section supplements Hodge’s review is that this is the only distinct category of SAT that did not fit into his review. Other SATs are included within his categories, particularly the section on Spiritual History.

<sup>171</sup> Professor of nursing at California State University, Northridge

<sup>172</sup> The patient at the time of the assessment, due to their condition at the time, had been unable to give information.

<sup>173</sup> These difficulties have already been discussed in Chapter 2

has not yet moved in that direction, it is useful to observe the features of SATs already being used by professionals.

In the European healthcare context, many SATs are being borrowed from the US and an *ad hoc* approach to the implementation of SATs is emerging as publications propose a variety of ideas for implementation, rather than report on settled good practice (McSherry and Ross, 2010). The UK healthcare context is in a transition stage at present and so it is important to note the response of healthcare chaplains who have worked in cultures such as the US and Canada, where SATs are more established. This allows discussion to focus on the functionality of these tools as experienced by professionals who are using them, rather than on the promotion of SATs.

Whilst Hodge was engaged in encouraging good practice in the field of social care by matching the right tools with the right people, attention now turns to reports of non-engagement by healthcare chaplains in intentional documented SATs<sup>174</sup>. Concerns about non-engagement are identified by Thomas O'Connor<sup>175</sup> et al. (2005) in an article entitled “Not Well Known, Used Little and Needed: Canadian Chaplains’ Experiences of Published Spiritual Assessment Tools”. The exploration of this study may allow me to avoid such features, so that I may deter a lack of engagement and instead assist in the introduction of a SAT that healthcare chaplains wish to use; due to its design being compatible to their work and the people they care for<sup>176</sup>. I will examine the work of O’Connor et al. in order to critique the application of SATs and assess the experiences of healthcare chaplains who have used them.

O’Connor et al. conducted a quantitative and qualitative study into the use of SATs by members of the Canadian Association for Pastoral Practice and Education (CAPPE). As a significant percentage of CAPPE members were working in a healthcare context, this study

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<sup>174</sup> An intentional documented SAT describes the shared process between a professional and a patient of gathering of specific information to enable the MDT to provide appropriate spiritual care.

<sup>175</sup> Associate Professor and Director of Pastoral Care and Counselling, Waterloo Lutheran Seminary, Canada

<sup>176</sup> In term so of the clinicians, the deterrent was not so much the tools they used in assessment but their primary focus was not spiritual or religious (Hathaway, Scott and Garver, 2004 p.100; Armbruster, Chibnall and Legett, 2003, e.231; Chapman and Grossoehmne, 2002, p121). Another issue is the perceived role made by the patient. A study of adult patients indicated that that they did not present spiritual needs to nurses (Cavendish, Konecny, Naradovy, Luise, Como, Okumakpeyi, Mitzeliotis and Lanza, 2006, p.41). Another nurse led research project found that proactive measures were required in assessing spiritual needs in a paediatric setting (Dell’Orfano, 2002, p.385).

has particularly relevance to this thesis (O'Connor, 2005, p.99). One third of those surveyed had used a personal or specific site associated assessment tool. However, around half of respondents had not heard of the 23 spiritual assessment tools profiled in O'Connor's article and no respondents reported always using a SAT.

The study found that many chaplains use their own SATs, indicating the importance these chaplains attributed to such tools. However, despite the plethora of tools available, many chaplains do not use them in their daily work. It would appear that some healthcare chaplains have little confidence in SATs and that this may potentially discourage other healthcare professionals from considering them as a viable approach to patient care (O'Connor et al., 2005, p.103).

O'Connor et al. found that difficulties associated with the non-use of SATs were due either to the nature of certain chaplains' approach or due to a design flaw in the SAT. The main factors that were reported as deterring chaplains from using the SATs were their confusing and "cumbersome" nature and inflexibility in a specific context. Some respondents also reported that using SATs affected the intimacy of the patient encounter by distancing the chaplain from the patient. These results indicated that "there is a huge gap between published spiritual assessment tools and clinical work" (O'Connor et al., 2005, p.105).

In order to avoid these problems being replicated in this study, it is necessary to examine in detail the four main problems found in O'Connor's study. The first was the reaction of healthcare chaplains who were disenchanted by their experience of existing SATs; raising a catalogue of concerns, ranging from the time taken to use SATs, to their general complexity in application. This led to disengagement which, in turn, produced a lack of awareness of other SATs that could be adopted. These chaplains did use some form of spiritual assessment, but had not engaged with the selection of SATs identified in the study.

The second problem related to the irrelevance of SAT tools to the specific contexts chaplains worked in. Chaplains often found that using a SAT could negatively affect the pastoral encounter and focused on details that were not of interest to the patient.

The third problem related to how well SATs could be integrated into the work of the multi-disciplinary team and the extent to which the tool offered "a framework that helps the

chaplain understand the patient” (O’Connor et al., 2005, p.105). As the SATs examined in the study were self-contained, their structure did not relate to the structures already used by multidisciplinary teams to understand their patients.

The fourth problem related to the ambiguity chaplains felt about the place of published SATs in the context of their work. Views on this were divided, with some chaplains identifying that they already used categories similar to those in the SATs and that there were similar reference points in their own assessments of a patient and others reporting that the use of SATs interfered with their work. It was disconcerting that some chaplains suggested that the very purpose of SATs, the improvement of care, was negated and that in some cases they suggested that the level of care was diminished.

Despite this unwillingness by Canadian healthcare chaplains to engage with SATs, the research into SATs appears to have reinforced confidence in their own individual processes of spiritual assessment of their patients. The challenge for this study is to introduce a SAT which can be accessible to healthcare chaplains and can enable them to collaborate with the rest of the multidisciplinary team (Power, 2006, p. 16). To achieve this, it is necessary to design a spiritual assessment tool that is appropriate to both patients and professionals so that both feel equipped to use it confidently and find it to be useful.

A multi-disciplinary team (MDT) in a healthcare setting assumes, as part of its professional practice, that the care of the patient is shared and owned collectively by the care team (Desai, Ng, and Bryant, 2002, p.88; Govier, 2000 p.6; McClung, Grosseohme, Jacobson and Ann, 2006, p.151; McSherry, 2006, p.912). This sharing and collective ownership of care should include the provision of spiritual care. Even if a healthcare chaplain routinely conducts an individual assessment of each patient, this may not constitute a collaborative approach to care (Johnson, 2001, p.181). The responses recorded by O’Connor et al. strongly suggest the presence of a territorial and defensive stance on the one-to-one relationship between patient and chaplain. This attitude runs counter to the need for the chaplain to embrace the “hospital community” (Cobb, 2004, p.10; McSherry and Ross, 2002, p.483). A SAT gives the hospital community a way to address spiritual needs collectively and, in so doing, challenges the individualistic approach to care. Where appropriate, responsibility for the provision of spiritual care could be shared by members of a MDT other than the chaplain (Weaver, Pargament, Flannelly and Oppenheimer, 2006, p.338). This could only take place if the

chaplain shares information received with the MDT in a way that can be understood and used by other professionals.

The work of Hodge's and O'Connor et al. provides the basis for design features required for a SAT to be appropriately applied and accessible to both the assessor and the patient. The complexities of the paediatric dimension have not been considered by proponents of SATs, and no examination has been carried out of assessor awareness of the cognitive level of a child. Additionally, none of the SATs identified in the overview were described as possessing features where children could engage with a method of assessment consistent with their stage of development.

However, features have emerged from the overview that have affinity with the design principles already identified; that SATs do focus on a patient's sense of purpose and, to a varying degree are relevant to a patient's "ultimate concern". All the SATs reviewed were viewed as being safe, in terms of providing a process which ensured a safe environment for the patient and where the assessor entered a protective and guiding role. The extent to which the assessor adopted a liminal role was not explored. Some of the visual SATs could be described as a "joint activity dyad" as patient participation was encouraged. This is the closest format, in the above SAT overview which could be described as a molar activity, termed a "proximal process". However, none of the SATs included in the preceding overview feature play or storytelling.

### **E. Developing the design of a Spiritual Assessment tool for a Paediatric setting**

This chapter has provided an overview of the type of SATs used in practice. In the following section, I apply the principles identified in the previous chapter to the various issues raised above in preparation for devising a SAT suitable for use with children. While the selection of SATs above are drawn from those used with adults, they form a valuable reference point from which to further explore the principles applicable to the use of a SAT with children.

#### *1. The need for giving extra time to conduct a SAT*

Hodge identified the duration of the interaction with the patient as an important design feature to consider when creating a SAT. This aspect was also recorded in the focus groups of O'Connor et al:

Time constraints and the cumbersome nature of the tools were mentioned a number of times to explain why people did not use the tools they knew (O'Connor et al., 2005, p.104).

The healthcare professional conducting a SAT with a patient should vary the length of time needed, depending on the amount of data to be gathered. Hodge suggested that much of the information received using a SAT would not be pertinent to addressing the spiritual need of the patient, and that it is important to establish what information is required in order to avoid wasting time. However, the nature of the information sought, as well as the nature of the person being assessed may also determine the length of time needed for an assessment.

Despite these measures being taken into consideration, re-apportioning time is an intrinsic tension that cannot be removed or ignored in the design of a SAT. Hodge and O'Connor's work indicates that the introduction of a SAT requires a chaplain to adopt a different working practice, logistically and systemically. The management of the chaplain's own caseload, and the way in which information is shared, are key factors in determining the benefit of an assessment. The outcomes of an assessment are important not only for the assessor but also for the multidisciplinary team they represent. For example, although more time may be required to complete a SAT, it may prove to be a good investment for the overall care of the patient and, perhaps, lead to a reduction in time invested by the team overall. While the process might use more of a healthcare chaplain's time, it may be time well spent if the patient's care is more effective as a result. In rejecting a certain style of SAT in order to reduce the time taken to use it, there is a risk of not achieving the desired goal because the information gathered may be insufficient or not useful.<sup>177</sup>

Therefore the issues related to lack of time, raised by chaplains in O'Connor et al.'s study, may suggest a need for a change in working practice. If a SAT invests time in play and storytelling, an assessor would need to ensure that such a design would yield valuable information about a paediatric patient.

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<sup>177</sup> If content and style are closely interrelated and it affects the focus of the information when a healthcare chaplain uses a SAT with a patient then it is crucial that both the style and content relate well to children. In terms of the content this has been established through the infra structure supported by the combination of child development theories in the previous chapter. In terms of style this is to be addressed in the following chapter

## *2. Enabling Collaborative Working with the Child*

Some healthcare chaplains surveyed felt that SATs interfere with spiritual care, suggesting that for the SATs to be accepted they must be intrinsic to healthcare chaplains' practice in understanding the needs of a patient. Developing a more transparent and intentional SAT that is understood by the MDT, optimises the possible outcomes of such an assessment through collaborative working practice. It moves towards a situation where a healthcare chaplain can share with the MDT, who would have informed assessment criteria for how spiritual care should proceed. In addition, O'Connor et al. indicate that SATs were only engaged with positively when both chaplain and patient felt they could engage in a collaborative task.

Hodge's review indicates that different styles of SATs appeal to different types of patients. For example, he identified that a Spiritual History SAT can appeal to verbally-orientated patients due to its flexibility and ability to enable patients to express their unique story. Those who are not verbally-orientated may feel intimidated if expected to share information in this way. Hodge suggests that some patients may prefer a more structured framework. It is important for me to incorporate into my SAT principles which allow child and chaplain to be partners in the assessment; there must be an affinity with a child's cognitive style; the SAT should be consistent with the child's stage of social development; it should tap into a child's "ultimate concern"; and engage appropriately with a child's "proximal processes". The focus on proximal processes alludes to visual elements which invite play and storytelling, which is developed further in the next chapter where methodology is discussed. These core design principles will give the integrity needed for a paediatric patient to share information. This in turn will reassure the healthcare chaplain that this assessment task allows them and the patient to achieve the intended goal of a clear and insightful assessment.

## *3. The visual content and direction of questioning determines the focus of information gathered in a SAT encounter*

It is apparent from Hodge's review that the design of a SAT should address the needs of the person being assessed. Hodge highlights how the visual design of spiritual life maps can allow patients to be more attentive to current social factors, rather than focussing on past influences in their life. In designing a SAT for use with children, it is important to understand the needs of children in hospital, and the impact of illness and the healthcare journey. The relevance of the aspect of children's lives outside of hospital would be in how children relate to these while in hospital. The visual aspect of the design assists in profiling the ecology of

children and how they describe their lives through the disruption of their contextual framework.

#### *4. The design of the SAT determines the type of skill set required by an assessor*

For a SAT to be used effectively, an assessor must possess particular skills in order to carry out an assessment that will improve the care of the paediatric patient. The assessor must be able to engage at a level at which children feel they can share information, in order that they can feel secure and safe in the environment and the manner of engagement the assessor offers. Therefore, the design principles which shape both the style and content of a SAT dictate the skill set required by a healthcare chaplain in conducting that SAT.<sup>178</sup>

#### *5. The need for an accessible conceptual language for multidisciplinary working*

There is a clash between the current working practice of some healthcare chaplains and the thinking underpinning the SAT being proposed in this thesis. For an assessor to share information with other members of an MDT, the assessments carried out must be understandable by the team, even in his absence. A new conceptual language must be devised which can describe the outcomes of the assessment process in a way that is clear and cohesive to those unfamiliar with concepts of spirituality. This is a critical factor in the cultural and professional shift involved in moving away from the language of 'spirituality'. A healthcare chaplain needs an interpretative tool to relay effectively and clearly the spiritual needs of children to other professionals in a multi-disciplinary team.

In order for this to happen, adjustments must take place in the process of spiritual assessments made by healthcare chaplains. This highlights the agenda of this thesis; that interpreting children's spiritual needs requires the embedding of building blocks from the study of child development as the interpretative means to share the findings gathered from conducting a SAT. Identifying and sharing findings from the SAT is a necessary skill for an assessor to possess.

A new concept of childhood spirituality must be clearly understood by all professions who engage with the child in hospital. A healthcare professional requires the competency to communicate this interpretative framework, so that other professionals can respond on the

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<sup>178</sup> In Chapter 8, this thesis seeks to establish that the profession most appropriate to conduct a SAT is a healthcare chaplain because of the competences they possess.

basis of the information produced through the use of the SAT<sup>179</sup>. This is an effective application of the healthcare chaplain's spiritual assessment skills which assist other professions to offer better care to the patient<sup>180</sup>.

### **F. Summary of the Attributes to Project into the Proposed Methodology Explored in this Thesis**

Despite the fact that Hodge's overview does not review a SAT used with children, it clearly illustrates some design principles which could be applied to a spiritual assessment tool in a paediatric setting. It sets the parameters for a SAT that is accessible to the patient, gathers the required information, uses the chaplain's time well and can be shared with others.

Hodge's review reiterates that the appropriateness of a SAT should be judged not only on the nature of the information to be gathered, but also on the manner in which the data is collected. The design principles drawn from the field of child development are key to the manner in which data is collected from children.

However, O'Connor et al.'s study also reveals that it is crucial for a healthcare chaplain to be confident that his contribution adds to general patient care. This highlights the need for the chaplain to possess an appropriate skill set to enable proper engagement with the SAT methodology.<sup>181</sup> It is clear that a healthcare chaplain must have an interpretative framework of spirituality through which to filter the information gathered. Hodge's poor selection of an anthropological interpretative framework demonstrates that the conceptual choice must suit

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<sup>179</sup> A study identified several common features of paediatricians who raised spiritual and religious issues with patients more than their peers (Grossoehme, Cotton and Leonard, 2007, p.197)

<sup>180</sup> Therefore, consideration would need to be given to the design of the SAT portfolio under study in this thesis not just to the information sought but also to the impact of the layout and how that affects the focus of the patient and the information they yield as a result of the visual design. It might offer the necessary focus, it may provide safety for the patient and assessor or more negatively it could unwittingly censor thought processes and connections that needed to be made.

<sup>181</sup> This is what it might mean from these initial deliberations, for a healthcare chaplain but what might it mean for a paediatric patient in relation to the overview in this section of the thesis. If such tools were used in the formats presented and if professionals themselves feel intimidated by using such tools what approach would be conducive and appropriate in preserving the spiritual care encounter by a child. In Chapter 3 indication was given by Bronfenbrenner that such connection was made through play. Therefore consideration is given in the next chapter to the place of play as a means to gather information and to engender and nurture the pastoral contact through a play format for a spiritual assessment tool.

the professional setting where it will be applied. The healthcare chaplain should be able to communicate with other professionals using the chosen framework. It is important to have a good balance of information which gives insight into the patient as an individual, the context of the care and influences on the child's present and past situation.

The identified gap in SATs in the above overview in relation to the absence of research on SATs suitable for use with children and the questions raised on the design issues in relation to the importance of collaboration with healthcare professionals, add to an exploration of the extent to which play and storytelling encourage and facilitate a child to share in a safe and secure setting. This sets the scene for the development of a spiritual assessment tool for use with children in hospital, which is the focus of the next chapter.

## **Chapter 5: The development and shaping of the design of the SAT portfolio**

### **A. Introduction**

Chapter 3 described the importance of storytelling and play for sick children in hospital and highlighted how adults who wish to understand a child's internal world must engage with these resources. Chapter 4 established that Spiritual Assessment Tools (SATs) must be appropriate, accessible and administered by a trained assessor. However, none of the tools reviewed employed storytelling or play and none took account of the social developmental issues which a trained assessor should be aware of when working with children.

This chapter will respond to these challenges by charting the ethics, design and testing of a SAT constructed specifically for use with children and administered by an assessor aware of the ways in which children make sense of, and meaning in, their lives. It will describe my initial efforts to use the new SAT with children, and also describe the ways in which the portfolio was adapted during the process of testing. The development process for this tool was lengthy and many of my existing preconceptions, such as acceptance of the traditional terminology of spirituality, were challenged during the process of development. I made many false starts and mistakes, but my reflections on these were important to allow for changes which have been of positive value in producing a SAT portfolio that is fit for purpose. The chapter concludes with a case study, describing the use of the final version of the SAT portfolio with one child.

The SAT comprised two main tools that were used throughout; sorting cards and a storyboard. The sorting cards carried images intended to reflect the everyday life of the child, such as images of family, pets, toys and food. The cards were used to play sorting games with the child, in conjunction with the use of the storyboard. The child would select and 'sort' the cards placing them on the storyboard (Kendall, 1999, p.65). The sorting cards and storyboard were placed in front of the child so that the visual images triggered conversation. The child would be asked to select cards which portrayed images relevant to their feelings whilst in hospital, and would rate those feelings by placing the cards on a visual Likert scale. Through placing cards on the board, participants were invited to name issues, events and emotions of significance to them. The storyboards were used to facilitate and encourage imaginative story telling by the children. A full illustration of all components of the SAT at each stage of

its development is given in Appendix 9; readers may find it helpful to consult this when reading this chapter.

## **B. An overview of the ethical requirements for conducting the research project.**

### *1. Introduction*

The importance of ethics in this thesis stems from the selection of human participants in a particular context; specifically, that it was conducted with sick children in a paediatric healthcare setting. Ethical issues addressed here are the need to 'do good' (beneficence); the need to minimise harm (maleficence); the need to ensure that informed consent is obtained; the need to ensure confidentiality and anonymity for participants; and the dissemination of information. The final section addresses the additional ethical issues which must be considered when the researcher is also located within the data itself; such as the researcher's reflexivity, and the naming of interested parties to ensure the creation of a transparent research process.

### *2. Background – the selection and nature of the methodology used in this thesis in relation to the ethical considerations*

The rationale for selecting a certain research methodology was to ensure that the children involved in the study would provide the data required for the knowledge sought in this thesis. According to Greene (2005, p.4):

Setting out to research children's experience implies a respect for each child as a unique and valued experiencer of his or her world. It also demands the use of methods that can capture the nature of children's lives as lived rather than those that rely on taking children out of their everyday lives into a professional's office or 'lab'.

The research in my thesis aims to understand childhood spirituality in a healthcare setting from the perspective of the child. The principal research question of this thesis is, "In what way does a spiritual assessment tool facilitate the chaplain in delivering spiritual care to hospitalised school-aged children?" Addressing this research question involves the consideration of the ethical dimensions of the project in this thesis. All research with human participants requires ethical clearance as the rights and safety of an individual must not be contravened. Conducting research with children (a vulnerable group) is ethically challenging

in relation to informed consent, as they may be disempowered and more easily influenced. As a result, additional consent from parents or guardians is required. Research with children requires the researcher to provide information which is appropriate to their developmental level so that they can make an informed decision about whether or not to participate in the research (Oliver, 2010, p.22, 36; Robson, 2002, p.70). When children are sick the ethical dimensions are more pronounced. The child's state of health means that they could be suffering a level of distress that may make the decision to participate a stressful one, and prevent them from being able to make reliable decisions. Additionally, children's location in hospital, where they have little control over their environment, may lead them to feel obliged to participate in the research when asked. This means that consent from other gatekeepers (healthcare professionals) is also required to ensure that an appropriate decision is made (Oliver, 2010, p.111). While the acute nature of the participants' context makes these ethical issues more complex, the fundamental principles of ethics remain the same; measures applied in this research project must be consistent with the ethical principles of beneficence, informed consent and confidentiality/anonymity.

Appropriate ethical bodies gave approval for the research project contained in this thesis to be carried out. The research was based in the NHS and part of a PhD in the University of Glasgow. In line with standard procedures, this required two applications for ethical approval; one to the University of Glasgow and another to the National Health Service (Speck, 2008, p.14). The body representing the ethical responsibilities for the National Health Service is the Central Office of Research Ethics Committee (COREC). Copies of the documents which comprised the application to COREC are contained in Appendix 10. Once approval was granted by COREC, an application was made to the University of Glasgow Research Ethics Committee which included details of the COREC approval. The COREC approval provided the basis of the University's ethical approval. The following sections address the ethical principles of beneficence, informed consent and confidentiality/anonymity, and how these translated into the research project contained in this thesis.

### *3. Ethical Principles*

#### *a. Beneficence vs. Maleficence*

A primary ethical concern is whether research conducted may cause harm; the assessment of the beneficence or maleficence of a research project. In relation to beneficence the Belmont

Report states, “(1) do not harm and (2) maximise possible benefits and minimise possible harm” (Kodish, 2005, p.22). Research should seek to benefit its participants, either directly or indirectly. This project aims to enhance understanding of how hospitalised children’s spiritual needs can be addressed, with a view to improving practice in this area in the future. Therefore, participants in this research may not benefit directly from its findings, but there is clear potential benefit for future hospitalised children. The potential of this project to do ‘harm’ to participants lies in the extent to which participation in the interview might cause upset or discomfort. First of all, current practice in healthcare chaplaincy has no research based evidence; it would therefore be unethical not to find out more, since without this research the safe practice of paediatric healthcare chaplaincy with children cannot be assured. Therefore, this thesis seeks to be the means to do good for a child; what Oliver refers to as ‘instrumental good’ (Oliver, 2010, p.11). Secondly, the methodology selected must complement the good it seeks to do. The interview must be considerate to the needs of the child and not be a harmful experience that a child finds unsettling or distressing in any way. The interview process also includes informed consent being provided, and reassurances being given to the participant.

b. Preserving the safety of the child - The impact of an interview up on the child

There are five elements in an interview in relation to beneficence:

- i) the conducting of the interview itself, which includes both
- ii) the manner by which informed consent is obtained, and
- iii) the assurances given to the child and parent. The assurances also include information about
- iv) the manner of dissemination that ensures the
- v) anonymity and confidentiality of the child. These five elements are now considered in this section.

i. The psychological and physiological impact of the interview

The methodology of the research in this thesis involves a child is being asked a series of open ended questions over a period of approximately 45 minutes, with another person (Bull and Gillies, 2007). This interview approach requires concentration and a measure of trust on the part of the child that may be tiring, given that they are unwell and may be in need of

treatment. The ethically aware researcher must be mindful of the time spent and energy expended by the child, so that this does not diminish a child psychologically or physiologically (Oliver, 2010, p.30, 68). To this end, interviews were set to take place at a suitable time, with the researcher assessing the child throughout the interview, to ensure that the approach was not psychologically intimidating and that the child was physically comfortable (Barter; Renold, 2000, p.318).

To minimise any harm to participants a staged approach was adopted, in which five cases provided the basis for decisions about methodological adaptations and changes which were implemented before the remainder of the interviews took place (Speck, 2008, p.15). This approach allowed for the opportunity to review the ethical dimensions of the interview approach after engaging with a small number of participants, thus minimising the potential for any harm to others.

## ii. Informed Consent

Informed consent is an ethical aspect that can empower potential participants to make a decision about participating in a research project based on a clear understanding of the project's aims and objectives and the implications of the choice to participate (Christensen, 2004, p.171). The potential participant can then make an informed decision based on a judgement of their own safety and the extent to which participation may be detrimental or beneficial to their healthcare journey. In a paediatric setting the provision of informed consent necessarily involves the parent and the child; by law a child under the age of twelve can give assent to participate only with the parent's consent (Kidish, 2005, p.12). Therefore, it is vital that the researcher provides full information on the potential implications of involvement to both the potential participant and their parent. This allows for a clear level of control on the part of the potential participant about whether or not to participate in the research (Oliver, 2010, p.56). The aim is to diminish any possibility of duress so that their decision to give consent is fully informed (Oliver, 2010, p.28). This includes giving details, such as the estimated time scale of the interview being 45 minutes.

The informed consent of child and parent in a hospital setting also requires the consensual co-operation of 'gatekeepers'; consultants and nurses who protect the child's health and well being. An approach to 'gatekeepers' was made possible by making an on-line ethical

application to COREC who allocated a code number when authorisation was granted (Oliver, 2010, p.39, 41). This code provided the researcher with authority to send a letter to all consultants on the hospital site, asking them to identify their preferred course of consent. Consent was given directly for each patient involved or allowed for the nurse in charge of the ward to act as the consultant's representative. This enabled me as the researcher to follow through with the procedure I had outlined with COREC of how potential participants in the study would be identified, approached and recruited (Appendix 10).

I made an initial visit to a clinical area within the hospital to investigate the presence of possible research participants that met the research criteria. I introduced myself and provided details of the research project and my role as a researcher. I raised awareness of the research project by providing information at meetings involving nursing teams and a range of levels of nursing management. After this dissemination of information on the research project, I then engaged in discussion with the nurse in charge of the clinical area and identified the consultant's preferred procedure for consent, matching patients with the research criteria. The nurse then approached potential participants prior to me making any contact with them, to ensure they felt no undue pressure to participate. The nurse offered reassurances to parents, confirming that the interview would not interfere with medical or nursing procedures or interrupt the patient's social life, e.g. visiting, education & leisure. The nurse also assured parents that interviews would not be held if the child was in acute distress, or if they became physically or emotionally upset.

Once consent was established I confirmed with the nurse in charge, or the consultant, the extent to which patients met the criteria for inclusion in the project (Speck, 2008, p.16). Criteria for inclusion in the research project were also explained to the nurse at this time, highlighting that the study should include children who were:

- Aged 6 -13 to enable a focus on child development
- Cognitively consistent with their age in mainstream education to ensure that the technique would be effective
- not in other research projects, to ensure unreasonable demands were not placed on the child.
- able to speak English, as I had neither the skills or resources to conduct interviews in other languages

- any faith or none to ensure the research was inclusive in terms of belief, and applicable to all in acknowledge the ethos of public service .

The criteria identify the limitations of the assessment tool in its current form in this research project, but it is hoped that the research findings will eventually be applied for the benefit of other children. Future research should consider engagement with speakers of languages other than English, and seek ways to overcome barriers to working with participants with visual impairment, so that the SAT can be used by a broader patient group.

Once the inclusion protocols were established I approached potential participants, with their parent/guardian present, to explain details of the research project. I showed the portfolio of materials that would be used, explaining to the child that their help was needed to tell a story and play a card game. I also explained that the visual nature of the information provided would require it to be filmed and an audio record kept (Oliver, 2010, p.47). I informed the child that the story board enabled them to participate, using character cards, in developing the plot with the researcher. Once the explanation was complete I left them with this information to consider. The reassurances given previously by the nurse were reiterated again by me. Providing an information sheet for both parent and child (Speck, 2008, p.14), I indicated that the assessment tool was not a test, and that I would return in 24 hours to ask if they had decided to participate. The information sheet was presented in accessible language and was age appropriate so that parent and child could each understand it and discuss it together. I emphasised that they were not obligated to take part and that they could change their mind at any point during the research.

### iii. Assurances

One ethical feature which has the potential to diminish any negative impact of involvement in a research project is to offer participants assurances throughout the research process. These measures remind participants that the onus rests with the researcher to correctly follow the research process.

Assurances were provided at the first point of contact, with the researcher reiterating that the participant could withdraw from participation at any given point. Assurances were provided that their contribution was not a test; that the research would not interfere with their healthcare; and that the data provided would be anonymised. These assurances aimed to

remove any sense of obligation that might cause the participant to persist with the research process by suppressing any discomfort; and to allay any fears they might have that any part of the process would leave them feeling more vulnerable.

These principles at the first point of contact were reinforced through the provision of a list of 'frequently asked questions' in a parental information leaflet and children's information leaflet (Appendix 2). The information leaflet also stated that if a circumstance arose that would require me to breach these guarantees, that the interview would be terminated. Assurances were also repeated immediately prior to interviews taking place. The guarantee would only be breached in the event that data divulged by the child related to the hospital's own policy on confidentiality, e.g. child protection issues. In this instance I would be required to inform ward staff of what had been disclosed to me and comply with legal requirements (Oliver, 2010, p.49; Robson, 2002, p.71).

After 24 hours I returned to the patient and parent and ascertained if they both wished to proceed. If a child indicated any uncertainty I did not proceed even if the parent was willing for them to do so (Kodish, 2005, p.9). In no case did a child wish to proceed if the parent was hesitant. In the cases where the parent and the child were both willing to proceed, I assisted with the completion of witnessed consent forms, and arranged a suitable time and location to conduct the interview; either at the bedside or in another suitable area in the ward. Three copies of the consent form were required: one for my own records, a copy for the family and child, and another to be placed in the medical case notes. Arrangements for interviews were made in consultation with the ward staff to ensure there were no interruptions or disruptions to patient care.

Before conducting interviews I established the child's belief and cultural understanding by asking the parent to answer a simple questionnaire (Kodish, 2005, p.9). This was not to confirm any set religious belief, but to ensure that any reference to a deity would be culturally familiar to the child (See Appendix 2).

Filming of interviews focused on the SAT and faces of participants were not captured, so as not to compromise the ethical principle of anonymity. Assurances were required by COREC that if "any topics or issues that might be sensitive, embarrassing or upsetting" came up during the interview that I had protocol in place to stop the interview. Although the ethical

application stated that this was unlikely, I was clear that if there was even a slight possibility that a child might become distressed when telling their story, the interview would be halted immediately and the parent or member of staff would be called to comfort the child.

#### iv. Dissemination and storage of information

To realise the aims of this project, and enhance the future spiritual care of children, it is necessary to disseminate the findings of this research. The application for ethical approval acknowledged that dissemination would occur through peer reviewed journals, an internal report, conference presentation or other publications. Specific steps were taken to ensure the physical storage of data was also secure. Data was stored in an encrypted format on an NHS laptop, or secure storage in the chaplaincy office. The information leaflets also detailed these above measures were taken.

#### v. Confidentiality and anonymity

The process of confidentiality and anonymity begins with an assurance provided to the parent and the child that participants are not identifiable through dissemination of information from the research project (Oliver, 2010, p.78). The data was gathered in a private environment, stored in a secure locked facility for 10 years and any shared data was anonymised to ensure that participants could not be identified (Oliver, 2010, p.81, 90). After the interview was completed the digital tape was transferred in encrypted format onto an NHS laptop. The data was anonymised, by identifying participants only by a case number and removing any geographical or other information given that might identify participants. The laptop was then placed in secure storage. The typing of the transcript was simultaneously anonymised, by replacing names with case numbers. Any video clips showing a participant's face were edited by the Medical Illustration department in the hospital, to ensure that the face was blocked from view and the child remained anonymous.

#### 4. Safety of the researcher

Reflexivity implies that the researcher understands that he or she is part of the social world that he or she investigates (Hansen, 2006, p.59).

There is the potential for psychological and emotional impact on the researcher as a result of direct involvement in gathering data, and because the researcher is part of that data (Swinton et al. in Denzin, 1998, p.3)

The ethical significance of a researcher being part of the data is that it becomes necessary to identify the impact on, or possible harm to, the researcher in the process of gathering data. The methodological design and supervision in this thesis acknowledges the predicted costs encountered by the researcher. There is potential tension between the researcher as a healthcare chaplain affected by the dominant therapeutic role normally delivered, and the diagnostic facilitating role used in this research. Likewise, as the researcher I was analysing the appropriate delivery of care, and the nature of the study placed an expectation on me as the researcher to be critical and analytical of my own practice. This had an impact on me as a healthcare chaplain through the reassessing of my current practice and the anxiety of this being exposed under close scrutiny. During this time I received supervision that helped me process any anxiety and feelings of exposure.

The involvement of the chaplain as the researcher could have compromised the validity of the research if the tension between my role as a practitioner and my role as a researcher had not been explicitly addressed. In order to minimise this tension, the research process involved a rigorous and robust approach through filming, transcribing and reflexivity so as not to compromise the data. This is an integral feature of qualitative research and addresses the involvement of myself as researcher and as chaplain. The reflexive processes of recording, analysing, supervision and journaling all allowed me to focus on the use of the SAT as a healthcare chaplain during the interview. During the analysing of the film I adopted a researcher's role so that I could reflect on the data collected and engage in the analytic process (Scharen and Vigen, 2011, p.19).

There is an ethical concern that funding bodies could influence the researcher's thinking. The naming of these bodies in the COREC application form serves as an acknowledgement that there is an ethical responsibility to name those interested in funding the project, and that there is no undue influence from those bodies on the presentation of the data (Oliver, 2010, p.19, 115). The declaration of the bodies funding this research project acknowledged my commitment to transparency and to objectify any possible influences in the research (Oliver, 2010, p.16). There were three such bodies:-

1. NHS Greater Glasgow Spiritual Care Department endowment funds.
2. College of Healthcare Chaplains
3. University of Glasgow

The declaring of bodies funding this research project was part of this background check, and provided confirmation that I was an employee of NHS Greater Glasgow and Clyde.

Disclosure of this information in literature provided to participants and parents enabled potential participants to refuse to take part if they did not wish to be associated with any of these organisations (Swinton, 2006, p.38).

### *5. Summary*

The above overview identifies the ethical principles that underpinned this project; beneficence, maleficence, informed consent, confidentiality, anonymity and the dissemination of information. In addition it has outlined the steps taken to address those principles in the context of a paediatric healthcare setting. The safety of the child's health and wellbeing was protected throughout by ethical protocols relating to informed consent, the retaining of the child's confidentiality and anonymity and assurances offered. The final section addresses the additional ethical issues which must be considered when the researcher is also located within the data itself. The nature of the insights sought through this research justifies the appropriate and accountable measures which were taken to enable the healthcare chaplain to also act as the researcher. The selection of methodology meant that the researcher as a healthcare chaplain took a reflexive approach that added to the awareness and interpretation of the encounter. The research has demonstrated that the ethical process was designed and presented to both protect and empower the child.

### **C. Preliminary profile of the refining process in Stage 1 and Stage 2**

The practical elements used for this SAT portfolio were developed as a result of making connections between existing ideas and my own practice. In my previous work as a parish minister I participated in the development and delivery of the local primary school's curriculum for religious education. In one project I presented a contemporised visual version of parables found in the gospel stories of the Christian Bible. Later, during my time as a healthcare chaplain, at a paediatric chaplain's conference, I was presented with the possibility

of using Godly Play in a healthcare context,<sup>182</sup> and subsequently explored this with a divinity student attached to Yorkhill hospital. The materials we developed used soft fabric, which was soon identified as unsuitable for a healthcare setting due to the need for infection control. Instead, working with the hospital medical illustrations department, I developed a range of laminated sheets and small card figures to make the storyboards, which are also used in this research. The sorting cards used in this thesis were developed from the cards created for the original storyboards; the variety of images on the cards were developed during my previous research conducted at Yorkhill (Bull et al., 2007) and the literature review for my MA (see Appendix 1). At this time I was already familiar with using playing cards in my routine work with children and telling stories with children at their bedside, and felt comfortable using these tools in my pastoral encounters with children.<sup>183</sup>

Changes were made to the storyboards and the sorting cards as the thesis research progressed. There were two distinct stages to this refinement process. In Stage 1 (the first five interviews), the sorting cards were used in an informal manner followed by the use of a story board and a selection of story card figures. In Stage 2 (cases 6 -16) the sorting cards were used in three visual exercises: the Likert Scale Exercise, the Accessibility Exercise and the Fruit Tree Exercise (conducted in that order) and these preceded the use of the story board.<sup>184</sup> These exercises and stages are discussed in detail below.

### *1. The Development of the SAT Portfolio: Stage One.*

In Stage 1, I hoped to replicate the experience of playing a simple card game with the children, and to discover more about them through conversation in the relaxed atmosphere created by the game. I asked participants to attempt a pyramid task, which involved identifying cards that represented people and activities in their lives. This task aims to find out what people, activities and locations are important in the children's lives. The pyramid task involved the interviewer and the child discussing and deciding on the cards selected. In

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<sup>182</sup> There has been a widespread influence of Godly Play with appropriate expressions of this in different contexts, (Hyde, 2004a, p.141)

<sup>183</sup> I knew that the visual approach was the way to make this accessible to children and enable them to share their views and feelings, (Driessnack, 2005, pp.415-416; Driessnack, 2005, p.1415).

<sup>184</sup> All interviews followed the protocol required for research approved by the Central Office Research Ethics Committee. This process required that each child was able to look at the portfolio to see what was involved before giving consent to take part. (For further consideration see (Coyne, 1998, p.409; Flannelly, Ellison and Strock, 2004, p.1231; Coyne, 1998, p.412; Hill, Laybourn and Borland, 1996; Kortelnuoma, Hentinen and Nikkonen, 2003, pp.435-436; Post, Puchalski, and Larson, 2000, p.580)

the process of doing so, the children were encouraged to identify cards representing people and activities in their lives, and to discard irrelevant cards. Sometimes discussion was required to establish the meaning to be attributed to a particular card. After this selection process, the cards were placed in rows in order of importance; the higher the row, the more important the cards were to the children. The cards in the lower rows were then eliminated. The plan was for ten cards to be left which would then be arranged into a pyramid shape, with the card at the peak representing the most important item in their lives and each level down being of lesser importance.

I also asked children to undertake an Accessibility Exercise in order to identify what aspects of their everyday lives were closed to them while they were in hospital. I hoped that the children's choices would help me to understand the child's network of meaning and to understand how their spirituality was affected by hospital treatment. The Accessibility Exercise used in Stage 1 took place after the pyramid task. After the construction of the pyramid, the children were asked to put the cards selected in that task onto one of two piles; one pile representing what was accessible to them in hospital and the other representing what was only available to them at home. The aim was to explore the extent to which their lives were affected by their hospital stay. Using this information the assessor would then be able to identify the spiritual needs to be addressed, by applying the interpretative framework to the data discovered.

While both these processes comprised a visual dimension, it soon became apparent that a more structured process was required, particularly during the Pyramid Task Exercise in which cards were laid out in rows in order of importance. Child 1, for example, swapped cards within the same row before swapping between higher and lower rows, and confusion increased when a new row of cards was placed above the current "most important" row.<sup>185</sup> He placed the card representing his grandmother on the top row, leaving the grandfather card in the second row. In order to understand the meaning of this, I asked for clarification. As a result, the child changed the card's position. I cannot know whether the child moved it because of an initial oversight, or because he felt obliged to change it after my intervention (Case 1, 29:20). The difficulty in discerning the child's thought processes was further underlined by the way he swapped cards between rows already placed down, despite my

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<sup>185</sup> This was a mistake made by me when the cards placed above would then be promoted as more important without consultation with the child.

confirming with him, prior to a new row being placed down, that the cards already in place reflected his choice (Case 1, 29:50).<sup>186</sup>

There were too many cards for Child 1 to prioritise and it was clear the child felt physically uncomfortable. It was difficult to discern if this was due to sitting in one position for too long, or if feeling under pressure led him to experience a physical awareness of discomfort, distracting him from the task. The effect was that the flow and confidence in the interview was interrupted ten minutes into the sorting card exercise. The child no longer swapped new cards even when one of those cards included representations of home and church (Case 1, 32:23). With prompting, he made a swap onto the second row which did seem to reflect his earlier discussions of these topics (Case 1, 32:32) and then made another straight swap with no knock-on effect. On reflection, I began to see that the task was too much for him (Case 1; 29:30). It was clear that a simpler structure was needed to create parameters to support the children in handling the multi-faceted nature of their world.

Dealing with such a volume of cards without structured visualisation meant that the children were so focused on the card they were holding, that they did not consider the effect of it on the existing prioritizing of cards.<sup>187</sup> This concern was discussed with my supervisors, who

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<sup>186</sup>Another difficulty that emerged during the prioritising of the cards was the way in which Child 1 made direct swaps with cards that were not in adjacent rows. While the importance of the promoted card was clear, the direct swap of the demoted card jumped over other cards that were originally less important. Was this just a matter of convenience for the child's arranging of cards or did this reflect the true position of the card?<sup>186</sup> The child was not consistent in this process. At other times he would make a swap that did have a knock-on effect on the cards (Case 1; 29:10). This inconsistency made it difficult to understand the decisions made by the child. It also underlined that this process was too difficult to understand the needs of the child and for the child to use.

<sup>187</sup>It was hard to understand whether the other cards were displaced as a result of conscious decisions or whether the children did not see the inconsistency of their latest decision over previous decisions. Child 3, who was a couple of years older, still had difficulties. The procedure involved placing one row of five cards and pushing up the cards which were important. Child 3 placed the first 15 cards fairly unambiguously. Cards were added and the same procedure followed. This was the first visible sign of an evolving multiple Scaling (Case 3; 33:10). However, as the volume of cards increased, straight swaps were made which indicated the same weakness of the SAT as before. This was rectified with a question or comment (Case 3; 34:00) but it would have been simplified by a more explicit scaling exercise provided by an embedded structured design which managed the child's decisions (Case 3; 33:20). When the child moved from three rows of five to four rows of five, it appeared that the amount of information was just too much to handle, underlining the need for a change in procedure to make the decision-making task simpler. The current format of the pyramid exercise and the accessibility exercise just

suggested that I introduce three distinct elements, or ‘games’, when using the sorting cards: The Fruit Tree Exercise, the Accessibility Exercise and the Likert Scaling Exercise. The introduction of games boards for these exercises provided a clear distinction between each task. Adopting these new visualisation exercises for the sorting cards marks the start of Stage 2 in the development of the SAT portfolio.

## *2. The Development of the SAT Portfolio: Stage 2*

The Fruit Tree Exercise involved using an A3 laminated picture of a brightly coloured apple tree with 10 red apples. The children were asked to place cards important to them on the ten apples (see Appendix 9). If the places were filled and they came across another card they considered important, they could swap it with a card they had already placed.

The aim of this revised exercise was to identify what mattered most in the child’s life whilst overcoming some of the ‘sorting’ problems that became evident during the pyramid task carried out in Stage 1. In Stage 2 the child was able to assign cards to places on the tree where they could be grouped together rather than having to be selected one over another. Choices would be made *about* the cards rather than *between* cards, thus avoiding such quandaries as, “all of these cards are really, really important” (Case 3; 39:10). Child 2 and 3 had required constant reassurance about making a selection throughout the process of the pyramid task in Stage 1 (Case 2; 28:10; Case 3; 39:10).

The Accessibility Exercise was used in Stages 1 and 2. The aim of this exercise remained the same in both stages, although the format was significantly different in Stage 2; when visual boards showing a picture of a house and a hospital were used as a place mat for the cards and to serve as a reminder of what each pile represented. In Stage 2, the Accessibility Exercise involved the children placing cards on the hospital picture (see Appendix 9), the home picture (see Appendix 9) or in a space in between. The cards on the home picture represented aspects of the children’s lives which could only be accessed when they were not in hospital. The cards placed on the hospital picture referred only to activities that could still be based at the hospital. The space between the images was designated for activities often associated with home but still accessible to children during their stay in the hospital. The use of this “in-

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didn’t work sufficiently. For example Child 3 expressed concern over the fact that comparisons were to be made between cards as opposed to a card being given a level of importance in its own right (Case 3; 39:00).

between” space was insisted upon by children when they didn’t want to select one over the other. This exercise, which was the least changed during the project, provided a sense of purpose for the children. When the three exercises were used together in Stage 2<sup>188</sup> the children were able to take control of the exercise whilst I sat quietly and observed.

The Likert Scaling Exercise was introduced in Stage 2 and involved the child placing cards onto a series of five faces displaying emotions from very happy to very sad (see Appendix 9) (Sexson, 2004, p.43).<sup>189</sup> This approach was less confusing than the rearranging of cards which took place in Stage 1, as the children did not need to make comparisons between cards, or give greater importance to any one card. It allowed them to make a significant distinction between what was important to them, and what they felt about the sorting cards they had selected as being important. The use of the Likert Scaling Exercise dispelled the anxiety felt by some children in Stage 1 when asked to decide on the importance of each card. The children appeared to have more confidence as to what was expected and were thus encouraged to engage with the process and maintain their focus.

Use of the Fruit Tree Exercise, the Accessibility Exercise and the Likert Scaling Exercise, helped the children to understand what they were being asked to do by breaking down the process into manageable and identifiable parts. The volume of cards remained a challenge throughout, but the Fruit Tree Exercise reduced the number of sorting cards to be considered.

I was satisfied that the changes made to the sorting card games greatly improved the children’s participation in the exercises. The introduction of structured, visual processes; the categorising of cards into groups; the introduction of new topics for cards; awareness of

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<sup>188</sup> The initial approach I adopted in this exercise indicated my tendency to introduce a therapeutic outcome demonstrating to the child how much of their life experienced at home still had aspects of it that were accessible to them while in hospital. While this procedure was appropriate for a therapeutic outcome it disguised the diagnostic significance of this information.

<sup>189</sup> It was used in Stage 2 and the Final Model. In Stage 2 it was the first of three exercises and in the Final Model it was the second of two exercises. The principle of using a visual Likert Scaling Exercise has been used in other research studies in relation to spirituality (Hall and Edwards, 2002, p.354; an example in McBride, Pilkington, and Arthur, 1998, p.59). There are others that become quite detailed (McSherry, Draper, and Kendrick, 2002, p.731)

alternative meanings given to cards; and the acknowledgement of problems such as managing the volume of cards, were all part of an evolving design process being refined through the experience of using the SAT. This process will be ongoing and through continued modifications, such as the addition of new relevant cards, the SAT could easily be made accessible to a wider age range, or to other contexts where children experience displacement and health issues, such as in a children's hospice.<sup>190</sup>

Having made significant changes in my use of sorting cards at the end of Stage 1, I was able to recognise, in Stage 2, that the role of the story boards should also be re-assessed. I came to see that the model I had adopted from Godly Play, of using modern parables, was not resonating with the chief concerns of the children in the study and was restraining rather than facilitating their own narrative agency. Furthermore, in order to gain useful information about the way in which children's spirituality functions in a hospital setting, the focus of the 'story' would have to be much narrower. This was achieved by confining the questions to the children's perspective of life in hospital, and also by introducing the hospital storyboard and sorting cards related to the children's healthcare experience. So from Case 16 onwards (Final Model) there was a move away from incorporating the children's stories into a storyboard of a contemporary parable, to using a storyboard which used an image of a hospital to enable a focus on their healthcare experience<sup>191</sup>. To illustrate the transition process in the project, I have selected the football trip storyboard from Stage 2 and compared it with the hospital storyboard of the Final Model.

The football trip storyboard was used by four children<sup>192</sup>. The storyboard was colourful, showing a grass green background with a winding road. Buildings represented different

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<sup>190</sup> At the start of this project, it was difficult to know what aspects of children's lives were important to them when they were in hospital. I did not want to exclude the breadth of content in the sorting card pack because I did not wish to limit the information I might gather. However, such an inclusive approach proved to be too difficult without a structured and managed process for the children and they needed many prompts to compensate for the lack of structured visual stimulus.

<sup>191</sup> This particularly affects the storyboards used for the shopping/football trip during Stage 2. (The Space Game was used by three boys before Case 6 and the Museum story board was only used once so little detailed comparison can be drawn from these examples.)

<sup>192</sup> Child 10 was a 9 year old boy being treated for e-coli, Child 11 was a 13 year old boy being treated for Crohn's and Child 12 was a 10 year old boy, who was knocked down by a car. Child 13 was a 13 year old girl

contexts of a child's life, such as home, work, school and a football stadium. During Stage 2 of the project, the interviewer set the structure of the context and the child filled in the events within the story plot. However I found that this approach did not allow freedom for the children to explore their own stories. The aim of using a story plot was to use the visual prompts to set the stage for free discussion. It was hoped that this discussion would include information about what happened in the children's home, or information about how their interests were pursued. I stated to Child 11; "what's going to happen is that you can make up as much of this story that you like. Ok it's down to you. You can be as creative as you like" (Case 11; 31:00). However, despite what I said, my actual practice with this child was different. It was only in retrospect that I became aware that I was not enabling the creativity I had hoped for, as the scope of the storyboard presented at this stage was too broad. I repeatedly questioned the child so that he would eventually focus on data related to the hospital. If the visual design of a tool had set clearer boundaries I would not have felt I had to intervene so much, and this would have allowed the child to talk more freely about his life in hospital.

When the interviews were conducted with a structured approach to a plot and using storyboards with broad contextual settings, it was difficult to transfer into conversation about the healthcare setting and the children's experiences in that setting. The change in the design of the SAT for the Final Model focused more on the healthcare experience of the child and, as a result, offered more direct information. It became evident, when using the hospital storyboard, that children's current situation was more immediate and vivid to them than their school or home lives. As a result it became clear that the focus of the SAT should be narrowed to the children's hospital experience and that they should be encouraged to talk about other contexts, such as home and school, from that viewpoint. The hospital storyboard was also useful in drawing out aspects of the children's healthcare which they found concerning the difficulties and expectations they had in relationships and the support that they appreciated during their stay in hospital. Creating an imagined setting, other than the hospital, generated extra work in the interview before the plot reached the point of the child's admission to hospital. Once the story focused on the hospital, the information was much more immediate and offered insight into what the child experienced.

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with Cystic Fibrosis. There was no parent or guardian present for all these cases. It is noticeable that this combination of children does not have their parents present during the interview.

### *3. The Development of the SAT Portfolio Final Model: The changed role of the healthcare chaplain as an assessor*

The third major issue affecting the use of the SAT portfolio lay in how SATs tend to be used by assessors, rather than with the SATs themselves. The focus of the SAT on the children's perspective on life during their hospital stay changed the role of the healthcare chaplain. If using this new approach, it is necessary for the chaplain's paternalistic, pastoral role to be superseded by a new one of facilitating, documenting and diagnosing; the chaplain must become an observer rather than an initiator.

It is through my own vocational journey from parish minister to healthcare chaplain that I have come to appreciate that a chaplain must listen to how children narrate their lives as patients and must interpret the spiritual needs of children using the information from that narration. This change in the understanding of my role is evident in the way I engage with the children and in how I reflect on that engagement. Through transcribing, reflecting, coding and documenting, I have continued to address the radical challenge to move from being a message-giver to a message-receiver.

In Stage 2, there was a structured plot and a range of contexts through which the children could describe their lives from the perspective of being a patient. It was hoped that this structured approach (Case 8; 38:30) would ensure that the interview addressed relevant topics. However, in practice the children did not always wish to proceed in the direction suggested by the story. Had they been allowed free choice, they might have chosen to explore an issue which was important to them. For example, in the interview with Child 9, when the context and the content of the story were set by me, no voluntary information was given by the child (Case 9; 27:30); her answers were single word replies and short sentences (my annotations record that I did not like the way the tool was working in the research setting). The plot was too restrictive and even when Child 9 made suggestions, I did not adopt them. I noted in my annotations that I was wrong not to follow up her suggestions. I also noted that "The other difficulty is my concern for time. The story suffers for being at the end of the interview as I try and negotiate to accelerate the plot". With Child 9, the annotations suggest that the problem was with more than just the structure of the plot and so I examined the style of the interview. The annotation at this point stated an observation about her statement, "That's all". On this I comment; "almost mumbled ... is she lacking confidence, am I being

intimidating?" The interview is as follows (R represents the researcher, P represents the patient):

R: What do you think of people visiting you? Does that make you feel good or...

P: Uhuh.

R: What visitors make you feel good?

P: I don't know.

R: You don't know. who visits you in hospital? ... Well I'll help you, mum? ... Who else?

P: My dad.

R: Your dad.

P: My gran.

R: Your gran.

P: My auntie.

R: Your auntie ... ok.

P: That's all.

R: That's all ... What about visitors like me who come in, and nurses and doctors, how do you feel when we come and visit you?

P: I don't know.

R: You don't know ... No you're not too sure.

P: No.

(Case 9; 36:00)

The interview became a mere formality from then on and the child gave little, if any, information about herself in the rest of the story. It was hoped that the story would provide a platform for discussion and give a context which enabled questions to be introduced. However, the terms of these discussions were not dictated by the child, but by the interviewer, and my focus was on the delivery of the story and not the receiving of the child's information. Focussing on the hospital setting allowed freedom for the children to explore their immediate context in more detail. Less time and energy was required to corral their focus to the desired content. When children were asked specifically about their healthcare journey, I was able to observe rather than intervene. Streamlining the design of the SAT to focus on one particular setting achieved this. The earlier design was too general, apparently offering freedom but, in reality, being quite restrictive. The freedom to roam in content meant

that insufficient data emerged which related to the child's healthcare journey, and so as interviewer, I had to guide the child to that focus. In so doing, the child's ability to share was restricted and I, as the interviewer, was adopting a style of interaction that was not facilitative but directive. In contrast, when a restriction was placed on the scope of the story setting, it allowed for more freedom in the dialogue between the interviewer and the child.

The interview with Child 14 illustrates this move from direction to facilitation. By using an approach where my interactive style focused on listening, rather than initiating communication, the child was able to set the scene for his character's home. The freedom he felt in doing this was apparent, as he described his arrangements with his friends and the purpose of the day. Apart from the choice of scene, my function as interviewer was limited to facilitating and understanding more about the child in the story. There were no long descriptive paragraphs to set the scene, as recorded in earlier cases. The benefits of this shift in approach were immediately apparent. In Child 14's interview, the themes of friends and computer games were used as the context of his story and it became clear that these were very important to him. If I had not conducted the Likert Scaling Exercise and the Fruit Tree Exercise to gauge the importance of these factors, I may not have realised the significance of his choices<sup>193</sup> (Case 14; 30:50).

When I asked Child 14 what he thought of the interview he said; "I was in control really. Whatever was going to happen, I was the one making it happen" (Case 14; 47:00).

Despite this comment, after I had transcribed the interview, I felt that the outcome I had hoped for had not been achieved. My comments were as follows:

I think this is one of the few times I asked the patient's opinion after the interview. It was helpful. Listening to this interview, it is apparent that, he is a boy who values friendship and family and both are present. I felt that I could have got more from the interview, as I was too preoccupied with the plot and context of the story and anxious to keep the time scale and sense of the story. There are areas to develop from this – particularly using the patient's illustration of being alone and down and thinking about things and also making a

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<sup>193</sup> This suggests that creating a more streamlined approach, combining the sorting cards and the storyboard, would be worth investigation

comparison that enables them to relate to the story and their own experience such as , "knowing how you feel in hospital what do you think this child felt."  
5/8/08.

The only element I requested from Child 15 was that her story should include admission to hospital (Case 15; 33:00). The rest of the structuring of the story was controlled by the child and facilitated by me. Afterwards, Child 15 began talking about the interview and I started recording again. She indicated that she preferred the Likert Scaling Exercise and that the approach throughout the interview felt unusual compared to her normal course of expression:

“Cos I was sitting and I'd be answering your questions. I've not really did that before. I've always chatted in ma ain way, the way I'm doing it just now. Because you're asking me questions I'm just answering them what's coming oot ma heed”.

(Case 15; 50:50)

Using the hospital storyboard, I was able to ensure that the discussion remained focused on the healthcare context. The facilitating role of an assessor constitutes a major shift which enables relevant information to flow naturally. Restricting my role to that of facilitator meant that more time was available for the children to express themselves while I ensured that the focus remained as their current perspective as hospital patients.

## **C. The Final Model**

### *1. Introduction*

This section will demonstrate that the implementation of the three refinements discussed above produced an effective final model. A case study<sup>194</sup> demonstrating the working of the tool in its refined form is recounted below. The procedure for the last four cases involved the Fruit Tree Exercise being used first, followed by the Likert Scale Exercise, and the sorting cards exercises were reduced from three to two with the removal of the Accessibility Exercise. The cards selected by the children were then used as part of the hospital storyboard developed especially for these last interviews. The first part of the interview, in the last five cases, blended the sorting cards with the storyboard by using the Fruit Tree Exercise to help

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<sup>194</sup> The use of case studies allow for specific insight into a particular practice, (Councill, 1993, p.79)

the children select ten cards in response to the question; “what matters to you most when you are in hospital?” These cards were then placed on the Likert scale to find out whether the children felt happy or sad about the images on the cards. The children then used these cards to tell a story about themselves in hospital by placing the cards on a picture board of a hospital<sup>195</sup>.

The change in the SAT involved a shift from the researcher focussing on the children, and their general life situation, towards examining how the children viewed their life from the perspective of the hospital setting. Although I believe significant improvements have been made in the SAT portfolio, its development is still an open-ended process, and other refinements need to be considered beyond this project. It is evident that the hospital storyboards and the content of the cards helped to focus the children’s thoughts and enabled me, as the researcher, to explore material from a perspective pertinent to the construction of a conceptual framework of spirituality relating to hospitalised children.

## *2. A Case Study: The merging of the three major changes in the final model*

### *a. The reason for using a case study*

The above analysis demonstrates how identifying and implementing these three major refinements have developed the SAT portfolio into an effective final model. It would be helpful now to examine a case study, using the SAT in its final refined form, in order to demonstrate how it functions in practice. For this purpose I have chosen to focus upon the interview with Child 18.

### *b. The selection of Child 18 as a Case Study*

There were several reasons why Child 18 was selected for this study. Firstly, Child 18 was assessed when the SAT was most refined. I did not wish to use the first case (Case 16) of the third stage as I was still familiarising myself with the changes that had been introduced. The last case, Case 20, included a different dimension as the child had specific educational

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<sup>195</sup>The storyboard was replaced by an enlarged picture of a hospital. A smaller version of this picture had been used in previous interviews for the accessibility exercise (see picture in Appendix 8).

support needs which only became evident during the interview.<sup>196</sup> Case 17 will be discussed in Chapter 7 to demonstrate the process of assessment. Child 18, who had a different health condition, is younger in age and is a different gender to Child 17.

*c. The Case Study*

During the interview with Child 18 the benefit of the refinements in the portfolio became evident when she showed concern that there would not be enough room for her cards in the Fruit Tree Exercise (Case 18; 11:00). I reassured her that this would not be an issue and was able to group all the family cards together in one pile to make room for any more cards she might select (Case 18; 12:00). I felt it was important that, in this case, the child was not expected to prioritise too early and be forced to discard cards that might have been important to her. Nor did I wish to cause anxieties over choice making as had been evident in the interviews in Stage 1. As a facilitator, I was willing for the child to structure the content, and to provide reassurance to ensure the smooth flowing of the game; I was also able to compensate for the child's readiness to discard a card too early. Constant consideration was required in order to be aware of how the visualisation process worked for children at different stages of cognitive development. Allowing swaps during the selection of the cards avoided premature decision-making. I was concerned (particularly in the case of Child 18, who was one of the youngest) that younger children might be more inclined to make quick decisions and not consider the effect of that for the whole game.

Prior to starting the hospital story board, Child 18 indicated that she might not want to use all of the cards (Case 18; 30:00) and I reassured her that she didn't need to. Such reassurances may be required so that children can feel they are in control of their story. The process of the SAT without facilitation by the assessor as "significant other" could overwhelm the child. The assessor needs to be sensitive to the appropriate level at which each child can engage. After reassurance had been provided, Child 18 was able to enter a new phase in the SAT. In preparation for the story, I laid out the cards she had selected and grouped them into activities and people so that these were easily accessible to her. The assessor must be ready to help the child to categorize and organize the cards. As I laid out the cards, I reminded her of what they denoted, particularly those that had been given specific significance during her hospital stay, such as the computer games card representing her Nintendo DS (Case 18; 30:00). I felt that I

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<sup>196</sup> This case referred to deserves further inquiry to explore the boundaries of the cognitive use of this tool but this is not the focus of this chapter.

needed to support the story by introducing a card representing Child 18, so that she could see that she was in the story. The interview with Child 18 is as follows:

P: (laughs)

R: Is that alright?

P: (Nods)

R: Well I didn't want to get a pet dog to pretend to be you! Do I?

P: Nooo!

R: No! So I chose that one just to help you so we can talk about that so the story has started with you and this is your mum because you have been chatting about your mum and you have been in Turkey but were you really really unwell?

(Case 18; 33:00)

At the start of her story, I selected the cards as she mentioned them. I had recalled that in the interview, we had partly told the story without selecting any of the cards referred to in the story. Therefore, I took an active involvement in selecting the cards as she told her story (Case 18; 33:00). She started to take responsibility for the cards, moving the TV card into the storyboard once we had discussed it (Case 18; 41:30). I affirmed this move as a “good idea” and she did the same with other cards.

The context of the “hospital” storyboard allowed the interview to develop well with this young child. I presented the clinical pictures as one group and explained the picture of the cannula, as the child did not understand what it was even though she was wearing one on her hand at the time (Case 18; 13:00; 14:00). The Final Model of the SAT helped the child to focus on, and share extensively about, her healthcare experience and how she perceived her hospital stay.

The Likert Scaling Exercise produced more insight into Child 18’s feelings about the intrusive nature of the cannula. Despite the limited nature of the exercise, it did tap into the child’s recall of what appeared to have been a distressing experience related to it (Case 18; 28:30). Using the cannula card highlighted that a doctor’s level of skill in administering a “jag” can make a significant difference to a child’s hospital experience. Child 18, who was 7 years old, knew the purpose of the “jag” and realized it was necessary for her cure. Whilst her preferred doctor’s administration of the procedure was not painless, it was less painful than

when carried out by other doctors and the child showed confidence in that particular member of staff. This can present difficulties when that staff member is not available. The discussion about the cannula went as follows:

R: You kept getting jags, wow and what were these jags doing?

P: They kept going on ma arm and on my ma feet and things.

R: Why did you have to get jags?

P: Because they had to check my blood to see if I'm getting ok and better.

R: Who does all that kind of stuff?

P: Em the doctors

R: And what is the doctor like when he comes in?

P: It got a wee bit sore but when (doctor's name) came in he did it a bit better.

R: He did it a wee bit better did he?

P: Cos doctors kept doing it like sore and when (doctor's name) came in he did it better and not really sore ...He did it not sore he did it this morning, cos he had to do it twice on my arm, cos one of the doctors did it sorely and (doctor's name) did it better than the other doctor that was in.

(Case 18; 42:00)

Child 18's experience of the cannula seemed to be the defining criterion of how she assessed her care and connected to her healthcare surroundings; particularly when the doctor was present. The hospital storyboard set a very clear context for her story. The focus was on the healthcare journey, the child's condition and the nature of the child's understanding of why she was there. The child's needs were evident in the way she recalled her story:

R: Did you feel sick unwell or did you feel sore unwell?

P: Em I was sick ... and getting pains in my side ... now I've got a tube in my side

(Case 18; 33:30)

Her needs were apparent from her matter-of-fact telling of the single aspect which made her scared; which was when she woke up from an operation and didn't remember or know those who were with her. In this instance I was able to reflect from my own childhood experience in hospital and this helped me to ask relevant questions. In my annotations from Nvivo, I

state that:

“This ties in with my reflexivity and what I recalled and it helped me to understand what she might have experienced and tap into a question that would open up an understanding into the child's hospital experience.”

27/10/09

This is an example of how the implemented changes in the SAT combined well and were effective in drawing out key data. The hospital pictures invited a flow of information from the child and this was enhanced by the interviewer's understanding of the nature of the child's healthcare journey:

R: And what was the operation going to do? Did you know?

P: I was asleep because they gave me milk because they had to put ma tube in ...  
magic milk.

R: Magic milk, what's that?

P: It makes me asleep when they do my operation.

R: ... what happened when you woke up?

P: I was kind of scared because I didn't know where I was

R: You didn't know where you were? Did you wake up in this room or did you wake up somewhere different?

P: Somewhere different.

R: And who was there when you woke up?

P: The doctor

R: The doctor, was it just the doctor?

P: Yeah ... I was worrying about my mum because she was waiting on me

R: Was she waiting on you. How did you forget? When your eyes opened what did you think?

P: I got all worried and scared

(Case 18; 37:00)

The changes in the SAT process resulted in gaining the desired insight into how the child (dis)connected with her surroundings.

## **G. Conclusion**

This chapter has provided an outline of the SAT portfolio, providing an explanation of, and justification for, the nature of the practical elements used and the timing of their use. It provides a background and context to the physical nature and development of the laminated cards used. It outlines the two stages in the design process and discusses the rationale involved in the changed procedural design. It has also described how the SAT was developed to the final and most productive stage achieved during this study and explained how a situation was reached where child and researcher would be able to work with the SAT together; drawing relevant data from the children's healthcare stories that could be interpreted and assessed. The design problems have been identified and areas for potential development have been highlighted. The hope is that this improved SAT will avoid the frustrations and distractions experienced by the children studied using the earlier versions. The following chapter focuses on the data gathered, making clear that in order to make use of this information an interpretative framework is required through which to collate, contain and communicate the data. The following chapter will indicate the spread of data and look at how the development of the interpretative framework can be achieved.

## **Chapter 6: What insight did the SAT provide into children in hospital?**

### **A. Introduction**

In this chapter, the theoretical basis for an alternative way to understand childhood spirituality converges with the practical application of the SAT with children in hospital. Three steps will be used over the next three chapters, to demonstrate the implications of that convergence; that the design of the SAT yields data; that the data can be interpreted in terms of a new conceptual framework for childhood spirituality (discussed in Chapter 7); and that certain skills have been identified which are specific to the process involved (discussed in Chapter 8). The first step will document the content of the data gathered in order to highlight the breadth of topics covered by the children. The second will consider a case study which will be viewed through an interpretative framework to demonstrate how the use of a SAT can help us understand a child's spirituality. The third step addresses the competences needed by an assessor in order to connect with children through the SAT. The competences required are shaped by the concept developed within Chapter 3, based on the study of the work of Vygotski and Myer, and will be referred to as the Zone of Proximal Connectedness (ZPC).

This chapter draws from interviews conducted during all stages of the research, in order to demonstrate the content of the conversations I had with the children. It contains observations on the comments children made about their healthcare journey in the hospital setting. Analysis of these observations will suggest how the children's perspectives might correspond with the psychological theories described in Chapter 2; theories which were used to establish the building blocks to reconstruct an interpretative framework for childhood spirituality. Particular reference will be made to the importance of the work of Bronfenbrenner,<sup>197</sup> in focusing on the ecology of the child and the various contexts that contribute to the child's experience.

In order to illustrate the children's perspectives and analyse the full breadth of the data collected, numerous extracts are presented from the children's responses to the various sorting card exercises<sup>198</sup> used at all three stages of the evolutionary development of the tool's

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<sup>197</sup> Piaget's work has greatly assisted in the design of the tool ensuring that the tool can be understood and used by a child. The work of Vygotski still needs to be applied to what I have referred to as the Zone of proximal connectedness (ZPC) and this will be evident in the chapter on the competency of the individual to connect with the child in a manner that allows the child to feel safe in sharing.

<sup>198</sup> Fruit Tree Exercise, Likert Scaling Exercise and the Accessibility Exercise

design (as outlined in the previous chapter). The material presented includes analysis of the children's perceptions of a familiar context, such as home, from the new viewpoint of a healthcare setting. This material will indicate the way in which children construct relationships to accommodate their awareness of multiple contexts. The manner in which children share information provides insight into how they connect with their surroundings. This serves as a basis for mapping diagnostic information gathered by using a SAT with a child. Mapping of connections or disconnections will be referred to as 'connectedness' or 'disconnectedness'. At this stage, this term will be used to locate where connection has occurred, rather than to identify the substance of this connection or disconnection.

Appendix 9 indicates the titles of the groups the cards were categorised into using the Nvivo software package. The group titles indicate the subject matter mentioned by the children during the interviews. I selected four themes, identified from the data collected; relationships; places in the community; activities; and clinical treatment.<sup>199</sup> The work of Bronfenbrenner, as discussed in Chapter 2, is a key influence on this study, as the content of the data can be mapped in relation to his Bio-Ecological Theory which also highlights how children make connections to these "systems".

## **B. Emergent themes**

### *1. Relationships*

One of the recurring themes in the interviews was the way in which children connected with other people, and even pets; the presence or absence of family members, friends or pets was mentioned frequently. The children's dislocation from their usual settings accentuated the disconnectedness from those absent from their lives.

#### *a. Family*

The importance to children of family whether parents, guardians, siblings or grandparents; was a recurring aspect of the relationship theme. For Child 9, this comprehensive understanding of family was evident in the Fruit Tree Exercise; when she filled all the "apple" spaces for what was important to her with picture cards of family members:

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<sup>199</sup> The process to reach these categories in Nvivo reflects other qualitative methods, (Graneheim and Lundman, 2004, p.108)

R: When you see that tree of all the important things, is there anything special about that tree?

P: It's like a family tree.

(Case 9, 26:00)

During the Accessibility Exercise, Child 6 demonstrated the importance of family in playing a supportive role:

R: Tell how you can do all those things when you are in the hospital?

P: Well your family can come in a visit you... and they can stay with you to try and make you feel better.

(Case 6; 18:40),

Child 10 made a similar point in the Fruit Tree Exercise. He was set on having his family represented on the tree when he said "pretty much all my family":

R: And when you've been in hospital does that help you to see how important your family are?

P: yeah

R: why is that?

P: my family are helping to go and making me feel better.

(Case 10: 27:10)

The SAT was able to cover a comprehensive understanding of what was referred to as "family," but this was broken down into different aspects by the children, as referred to in the following sections. It was apparent that children viewed family members as one group. Sometime a child's family network was so extensive that they had to be combined onto one space on the Fruit Tree Exercise; otherwise there would be no room to include other aspects of a child's life. In other interviews, children identified a wide supportive family network that did not involve their parents during their hospital stay, and demonstrated that they were conscious of the absence of parental support (Case 15; 16:00; 22:20). In either circumstance the assessment should identify what support is present and how the child understands it.

*(i) Parents or Guardian*

Various models of ‘family’ were found to provide a supportive network for the children interviewed; not only mothers and fathers. When Child 8 was presented with a card of a “grown up” man, this triggered her to share information that her “gran” was her guardian; she had contact with her siblings through her uncle and no contact with her mother and father. This led to an exploration of the feelings she had experienced since her mother had left, and she had been cared for by others. It appeared that the further dislocation from the child’s customary context may have accentuated the existing dislocation and brought it to mind. In this case, the child is separated from her brother, and her natural mother cares for a younger step sister:

R: Can I ask you why your mum can’t cope?

P: Well she... I don’t really know. All I know, she could cope and now she’s got a different wee girl...

R: How does that make you feel?

P: Well don’t know. Kinda sad cause she’s looking after another wee girl and not me... and everybody keeps...see how everybody I know stays with their mum and I’m not and so it kinda wants me to stay with her.

(Case 8; 23:00)

Child 8 shows an awareness of the responsibilities she feels her family should have towards her when her mother was no longer able to care for her. While in the hospital setting, the child is reminded of the loss of connection between herself and her mother, and she observes that other children have visits from their parents. I sensed the hollowness in her tone of voice when she told me her mother was now caring for another girl, who is not even her own child. The effect on this child was apparent, and the sorting card exercise enabled me to explore the family network. Interestingly, Child 8 still viewed her mum alongside her gran as making her happy,<sup>200</sup> placing her at the top of the Likert scale. When I pressed her on these contradictory feelings it transpired that the specific problem was her mother’s relationship with the other girl she cared for. It could be that these contradictory feelings are compartmentalized and the child carries these extremes of feelings, but when disconnectedness is experienced, the lack of what Bronfenbrenner terms as a “dyad” becomes apparent (Case 8; 26:50).

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<sup>200</sup>This was discovered through the Likert Scaling Exercise.

Child 13 described her mum as “oh that’s ma mum that could be, she makes me really, really happy” (Case 13; 18:50). She also provided detail about her stepdad and the types of activities he did with her. She expressed that her stepdad did not really need to fulfil these responsibilities and that it would have been natural for him to make a distinction between her younger step-sister and herself. The connections that the stepdad made in one context made her more able to make connections in a new context, being, as he was, consistent in both the home and hospital contexts (Sturgess, Dunn, and Davies, 2001, p.527). This contrasts with Child 8 above and indicates how a new context, such as a hospital, reveals the (dis)connectedness of the child.

When I asked Child 13 about her natural father, sadness and annoyance were evident. She appeared to be hurt that her father did not spend time with her, and that he focused instead on interacting with other children in the ward:

P: When I was a wee girl he used to visit...but not much.

R: Ok when you think about that how do you feel inside?

P: Sad and annoyed... Cos he’s, I don’t know, when he used to come he would talk to all the other kids and not me and stuff....so that’s why my stepdad’s the best.

(Case 13; 19:10)

The importance of Child 13’s family was clear from the presence of the cards in the Fruit Tree Exercise and the associated comments, and was underlined by their presence during her hospital stay (Case 13; 30:00).<sup>201</sup>

While children may appreciate the presence of an important relationship, it is greatly enhanced by how that person relates to them while they are in hospital. Child 8’s grandmother, her guardian, played a supportive role while she was in hospital. However, the support her grandmother gave did not seem to address the child’s needs, even though the child was aware of her gran’s good intentions:

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<sup>201</sup> Child 7 identifies the card for the grown up man as her dad straight away and also places him on the top of the Likert scale. He was described later as visiting hospital in the Accessibility Exercise (Case 7; 18:30).

P: Every single time I think about coming to the hospital I think about presents, presents, presents, presents and it doesn't work...

R: That's a soft big dog.

P: Uhuh My gran got me it.

... cos, see there on Friday, I had another operation on Friday. I had one on Thursday and one on Friday again, cause I've got these wee pin things ...and one of them has moved ... so they need to do another operation so she felt sorry for me, so she got that dog.

(Case 8; 10:30>>)

It seems that the child is saying that objects, or at least the copious numbers of them that the gran provides, do not address the nature of the connection the child is looking for. It appears that at this time in the relationship, the manner of connection adopted by the grandmother is not meeting this child's need.

A recurring theme was the importance given to the presence of a parent or guardian during a child's hospital stay (O'Briem, 2001, p.17). Child 14's mum was almost constantly present with him in hospital. He talked about this while carrying out the Fruit Tree Exercise:

R: And your mum? Tell me more about that you've chosen your mum.

P: Well my mum is mainly up still looking after me. She's up the most really most of the day and well sometimes she'll stay over

R: Uhuh, ok and does that make a big difference.

P: Uhuh

(Case 14; 26:40)

The SAT was effective in enabling me to discover the nature of the connections that this child made with his "family" both within and outside the hospital contexts. These examples highlight that a shift from one context to another can expose the (dis)connectedness experienced by a child. The use of the sorting cards enabled me to ascertain the parental or guardian support given to children during their stay in hospital. In some cases it also revealed the difficult emotional journey, related to these relationships, that some children have to navigate whilst also coping with their illness. The children did not talk about the decisions

that parents may have had to make to be with them in hospital; being more concerned about parents' absence from them, rather than what it meant for the parent to miss work to be present. This is what Bronfenbrenner refers to as the Exosystem; a context the child has no experience of, but which affects the immediate environment of the child.

*(ii) Siblings*

Using the SAT, it was possible to explore the relationships children had with siblings during their time in hospital, and to investigate how the children viewed the nature of these relationships from the context of the hospital setting. Child 6, for instance, placed the card representing her sister in the middle of the Likert scale. When I showed surprise at this decision, we were able to discuss the ambiguous relationship she had with her sister:

R: (sister's name) ok, where would you want (sister's name) to go on this one.... oh you're not too sure right, why is that?

P: Sometimes she can be really moody and sometimes she can be fun as well.

(Case 6; 2:20)

Later, she said that she had a brother who was 10 years older and she placed him slightly higher on the scale than her sister; "because he is fun" (Case 6; 8:12). Child 7 gave a similar response about her brother: "Yes sometimes he's nice, sometimes he behaves and sometimes he doesn't" (Case 7; 6:50). The description given by Child 16 of how she felt towards her sibling, showed the mixed emotions of a child in hospital when the sibling is present: "He makes me really happy and he makes me really sad...angry sometimes" (Case 16; 16:10).

Not all children reported ambiguity in their sibling relationships. Child 9 was positive about her sisters, although not much information was given (Case 9; 13:00). Child 10 had suffered from e-coli which resulted in him being isolated from his family for a period of time. The way he used the sorting card showed that he missed his brother and sisters, but also revealed the unifying role his parents had in trying to make and maintain the connections by phone.<sup>202</sup> The connection made between different contexts brought comfort to the child. He described

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<sup>202</sup>Bronfenbrenner might describe this as a joint molar activity

how he coped with the separation by trying to stay positive and think about seeing them at some point:

R: How do you feel inside when you haven't seen them for a while?

P: A bit sad.

R: Do you feel a bit sad? When you have those feelings what do you do?

P: Normally I try and think positive and I see them soon.....I tell my mum and dad too like when you are going to phone each other to tell them that I'm missing them.

(Case 10; 14:00)

Child 11 also seemed to think very highly of his brother and put a card representing him at the top of the Likert Scaling Exercise. The relationship was characterised by humour; a recurring theme for this child. Child 11 really appreciated the visits of his much older sibling. The element of surprise seemed to add to the impact of the visit. This helped the child to readjust his outlook to his present context:

R: Your brother (name) and why have you put it right at the top?

P: Cos he's my brother and he's hilarious... he makes me laugh so much...

R: Do you see him in hospital?

P: Yeah he came up last night

R: Did he right ok. How did you feel when he came up?

P: It was nice; I didn't actually expect him to come up.

(Case 11; 14:56)

Humour was also present in the interview with Child 12 who referred to his brother's antics during the "train travelling" card and the fun of being scared by him in a dark tunnel (Case 12: 9:00).

Child 13 had a 2-year old sister; an 11-year age difference. While she had to be patient with her on car trips, she was very fond of her sister who was represented by the baby or toddler card:

R: She's two and where would you put your wee sister on these faces?

P: There (*top of the Likert Scale*) cos she can be really funny...she shouts. When I'm in here she says, "Poor (patient's name) get better."

R: Is that right?

P: So she gives me a cuddle and that.

R: And how does that make you feel inside?

P: Happy a lot ....I feel sorry for her as well cos but I don't want her in my room sometimes...rid of them sometimes... and she goes up to me and she's cuddling me and all that and I'm like that.

(Case 13; 16: 10)

Child 13 appeared to have strong feelings for her sister but has to work through other feelings related to missing out on attention as a result of her younger sister's needs, as she has to negotiate her own space.

Separation from siblings seems to create a disconnection which can cause sadness, disregard, or a mixture of contradictory feelings. The tension of trying to make connections from different contexts can engender emotions which are difficult to handle; and yet, that disconnection can act as a momentum to reconnect to the original contextual framework that the child was part of. Child 14 placed cards representing his brothers in the Fruit Tree Exercise<sup>203</sup>. The reason he gave for their importance, even while he was in hospital, was the anticipation of seeing them when he eventually got home:

R: Your brothers there are not always in.

P: They're not always in, but we like...still think cos when I get home they'll be there.

(Case 14; 26:00)

By using the SAT, insight was gained into the children's relationships with their siblings. For some, it revealed the extremities of contradictory feelings that can be triggered by the same person. The presence or absence of a sibling in the hospital context can generate a diversity of responses for a paediatric patient. Some appreciate the space, if not the temporary disconnection, whilst others long to be with their siblings. The displacement of a child from

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<sup>203</sup> The sense of displacement is a motivation to be home.

one context to another affects children in many different ways and being apart from siblings is one more aspect to consider.

*(iii) Grandparents*

The sorting cards contained pictures of an elderly lady and man. It was hoped that these cards would encourage discussion about grandparents. The use of the SAT prompted information that indicated that when both siblings and grandparents are present in the life of the child, a stay in hospital may not be as disruptive. Child 6 used the cards of an elderly lady and man to represent her “granny” and granddad<sup>204</sup> and put them on the “happy face” on the Likert scale. Child 9’s grandparents kept a dog which was originally the child’s pet (Case 9; 11:20). Child 7 also placed both cards at the top of the scale (Case 7; 8:40). The importance of Child 7’s grandparents was underlined in the Accessibility Exercise when she identified them as visitors (Case 7; 18:20).<sup>205</sup>

Some of the children’s grandparents had died. Child 8 recounted how her grandfather died the night before she was born. This was a story that she had inherited and it had become part of her own history (Case 8; 1:40). Examples like this highlight that Bronfenbrenner’s chronosystem provides a contextual backdrop to children’s journeys and, in particular, shows that children relate to their past and apply it to their current context.

During the Likert Scaling Exercise with Child 14, it emerged that one of his grandparents had died. I followed this up to see if this information would reveal a spiritual need. It revealed his awareness of loss, but also that his level of grief was not as intense as he might have envisaged:

P: Well when my nanny died, I sort of felt, well she’s gone and I’m not going to see her again really, That was it, because I haven’t seen her that much cos it’s the one who stays in London. It won’t affect me as much because, like she wasn’t up here and haven’t seen her really.

(Case 14; 15:20).

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<sup>204</sup>I asked the question if she was still alive so as not to assume her existence through this exercise, avoiding any repeat of the Child 4 interview.

<sup>205</sup>This would be understood as a dyad in Bronfenbrenner’s Bio-Ecological Theory

This provided insight into the extent of the child's visiting network. It should be noted that, while this child responded in a matter-of-fact way about her deceased grandparents, a similar response in another child might indicate that they are still emotionally processing their feelings about a deceased grandparent. It is important to be aware of the implications of raising this subject in a potentially already fragile context, such as a healthcare setting.<sup>206</sup>

Child 13 also had a good relationship with her grandparents and the nature of contact and the way in which it was achieved was appreciated by the child:

P: And that's ma other granddad, he makes me stuff and watches videos with me and buys me stuff and ma granddad helps me draw and stuff.

(Case13; 16:50)

It is through shared activities that the connection is made between the child and her grandfather; illustrating the dyadic role that grandparents can play while a child is in hospital.

If some aspect of a child's environment remains constant, it may provide much-needed stability in a context where they experience a considerable amount of change. In Cases 6 – 11, grandparents were placed in the Fruit Tree Exercise but they were not mentioned during the hospital-focused questions. It is hard to deduce what this might mean. Perhaps it indicates that grandparents are important to children generally, but that in the specific setting of the hospital, they form a secondary supportive role to the child and parents (unless the grandparents are, as in Case 15, the primary carer).

The placing of grandparent cards during the Likert Scaling Exercise revealed the differing nature of a child's connection with the wider family; be that an awareness of companionship or loss. For some, the change in context did not disrupt that contact, while others only had a memory of a deceased grandparent. Many grandparents seem to provide company, show kindness through gifts and enter into activities. Introducing these cards raised issues of loss,

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<sup>206</sup>There is also a competency factor to include where the assessor would need to have the capacity to handle and process such information.

kindness, support, companionship, geographical spread of family and fun. They enabled discussion that provided insight into the range of family support available, and what that meant to the children.

*b. Friendships*

The “people” cards were used to represent friends by some children and the cards depicting play also triggered discussion about friends. The term “friends” did not necessarily mean “friendly” or friendship”. This was highlighted when Child 6 placed the “playing with friends” card at the bottom of the Likert scale:

R: Why did you put that one down there, playing with friends?

P: Because my friends don't really play with me at school...

I try to play with them but they always leave me out in the games. You're doing the skipping too fast, you need to go away and all of that.

R: Is that right? Your friends aren't really all that nice to you? Ok how does that make you feel inside?

P: It makes me feel really, really sad

R: And you've put it there too. And what does that make you feel about school?

P: I do enjoy going out but sometimes I just wish we couldn't go out and we just had to stay in class.

(Case 6, 10:20)

This discussion provided some insight into her network of friends in the school context, and insight into the coping mechanisms she had adopted in her relationships with them. This information prompted questions such as; “What support does she have in her school; will her discharge from hospital induce anxiety as returning to school comes closer?” It appeared that playground break times were a specific area of concern for her. After the interview I found that this was something the parent and school were aware of, and in this instance, using the SAT helped to identify this area of concern in this child's life. She was viewing the context of school from the perspective of being in hospital and anticipating the challenges she would face when re-integrating into the context which would again become her primary mesosystem.

Child 6's view of school from the hospital perspective shows the impact that separation from a normal home setting can have upon a child, for instance, the impact of missing friends or being marginalized by previous friends. This can be a concern for a child who depends on the knowledge of the stability of that environment, and the contact maintained with it while in hospital. However, the transient nature of a hospital stay did not deter this particular child from enjoying other companionship<sup>207</sup>. The hospital is not a static context in terms of generating friendships between children, and the ability to make friendships in new settings can provide a network that they appreciate. Child 6 gave the card representing friendship a new meaning in the Accessibility Exercise. She used it to speak of new friends she had made during her current stay in hospital:

R: What friends have you made in hospital?

P: (Patient's name) is my friend, and the boys next to me. I think he is called (patient's name) and the boy just down from me. They're my friends.

(Case 6; 20:30)

Child 9 also understood friendship as contact with another child (Case 9; 19:40). Though she was older, the discussion with her showed that she appreciated playing with another child when she talked of her experience and pleasure in babysitting. Both she and Child 12 showed their understanding of play with other children as a form of friendship (Case 12; 18:20). The contact with other children whilst in hospital is enough to be described as friendship and it serves as temporary substitute for the friendships the children have in contexts out of hospital. It constitutes a restructuring of their surroundings and demonstrates how they strengthen their stability by the links they make within their microsystem, through what Bronfenbrenner refers to as bi-directional influence.

Some children actively sought friendship in the hospital setting whilst other children struggled with this. The Likert Scaling Exercise helped to identify Child 7's feelings about friendship:

R: Playing with your friends, where would you like it to go?

*Child places it on a 'wee bit sad'.*

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<sup>207</sup> This dimension is not accessible to children with conditions such as cystic fibrosis.

R: A wee bit sad? Why would you be a wee bit sad playing with your friends?

P: Cos sometimes they don't let me join in.

(Case 7; 3:10)

Although the discussion revealed that friends played a part in her life, this response may suggest a lack of confidence in forming new friendships.

Connection between different contexts was often facilitated through technology. Children generally use mobile phones to stay in regular contact with friends and to arrange their lives. The inability to use mobile phones in the hospital setting, and therefore not have that regular contact, served to highlight their separation.<sup>208</sup> Child 15 used texting as a means of maintaining contact outside the hospital, in addition to using the hospital pay-phone. The importance of this to her was shown by the phone card being placed at the top of the Likert scale<sup>209</sup>:

R: Do you text your friends?

P: Yeah

R: So you've got that there as well. You don't have a mobile phone here to use?

P: No

R: So you're not able to text your friends as much.

P: No but I've got my pay phone and I can just phone my friends.

(Case 15; 7:00)

If contact with friends is curtailed by children being in hospital, how does this affect their sense of well-being? If contact with friends shaped their usual surroundings, then hospitalised

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<sup>208</sup>Child 7 had contact with friends by phone, when she was at home and enjoyed speaking to her friend over the phone (Case 7; 11:30). Child 9 also enjoyed this aspect in her friendships (Case 9; 4:40). Child 13 described the phone in similar terms but was more conscious both of the benefits and the drawbacks if she did not have enough credit (Case 13; 6:50). Child 10 was missing the contact he would usually have with friends and home because of no immediate access to a phone (Case 10; 6:10).

The use of mobile phones is a contentious issue and there seems to a hospital policy restricting their use but there is little credence given to it by the number of times I observe its use in hospital over the period of this research.

<sup>209</sup>The change in technology and communication in the hospital over this period of time is playing a significant factor in how children communicate, whether this be through mobiles, dongles on laptops or even through computer games.

children lose one of the means to link with other contexts and resultantly become disconnected.

Child 11, a 13 year old boy indicated, through the Likert Scaling Exercise, that he enjoyed playing with his friends both in and out-of-doors (Case 11; 8:10). When he was asked about not having this contact, he rationalized it by saying that since his friends were at school they would not be able to play outside anyway:

R: ...although it is a swing park it is more like going out with your friends to play or that kind of thing or meeting up with them.

P: Yeah.

R: And do you enjoy doing that, obviously, and how do you feel being in hospital and obviously not getting the chance to do that?

P: It doesn't bother me at the moment because they're kinda at school.

(Case 11; 5:30)

The introduction of one of the friendship cards to Child 12 revealed much about the importance he placed on friendships occurring in separate contexts. He placed the card that represented playing with friends inside, at the bottom of the Likert scale:

R: Playing with friends inside the house?

P: I hate playing with my pals inside ma house... I like playing with my pals outside the house I just like outside

(Case 12; 5:10)

This indicated that the child kept his family life and his friendships separate, and the time he had in hospital had the potential to bring these together, as friends and family may meet. It would have been interesting to see how Child 12 felt about his friends coming to visit him in hospital. In my annotations, I indicated that I anticipated his playing with friends outside to be at the top of the scale, indicating that it made him happy, but that was not the case. It appeared that he had activities with his family and interests of his own, but that he preferred to activities with his friends:

R: In the park somewhere ...ah right so in between. Can you tell me why it's just in-between?

P: Sometimes I don't like gonnae to the stuff and sometimes...dae. So it can be half and half... I can't be bothered do anything like ... cos, like school days and you're shattered after school and then Saturday and Sunday I've got football and you wantae come back from that and then they want I go run up big hills and that so...

(Case 12; 7:30)

Child 13's interview returned repeatedly to friendship and the activities related to maintaining friendships; on the computer chatting on the Internet, playing the PlayStation, dancing, singing, or listening to music. Her animated way of sharing about these showed their importance. Given this, it seemed that the role of her family would increase in significance whilst she was in hospital, if her friends were unable to be in contact; and this would be something for the practitioner to be aware of as a potentially significant factor.

Child 16 selected one of the cards from the "people" category in the Likert Scaling Exercise to describe her friend who had been to visit her in hospital (Case 16; 17:30). In contrast to other children who had little contact with friends, the benefit of the contact and conversation with her friend were evident.

The theme of friendship emerged frequently. The interviews examined the level of friendship in the network of the children's lives and what measure of contact was available to children while in hospital. The healthcare experience can also displace children's perspective of how they perceive their own position in the friendship circles they are absent from. Understanding children's concerns about their friendships might enable a practitioner to understand the adjustments they have to make while in hospital. Piaget's concept of "equilibrium" is appropriate here to refer to the thoughts of children who are trying to imagine the world of school and peers from the perspective of the hospital setting. Through Piaget's theory, it may be possible to assess the level of equilibrium a child has reached.<sup>210</sup>

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<sup>210</sup>Some children have repeated visits so they themselves can build up a comparison between what they perceived and what they experienced and this may accelerate the equilibrium as a result of repetitive in-patient hospital visits. These experiential factors can give variation to a developmental staged process and need to be taken into consideration to avoid a rigid assessment of a child. What also needs to be considered in conjunction with this is the interaction this child will have, as they explore this in their mind, with the likes of their parents or teachers and even the hospital staff. These connections will help the child understand and relate to a context they are absent from but wish to relate to, such as their friends in a school playground.

*c. Pets*

Pets played a significant role in the life of some of the children. However, whilst people can visit the hospital, pets cannot. The sorting cards included a picture of a pet dog and pet cat which were used from Case 6 onwards (see pictures in Appendix 9), and the cards were used frequently by the children. Mostly, pets formed a positive theme because the children were happy to talk about them and their attachment to them.

Child 6 was unusual in that she had a considerable number of pets and was able to describe them by name and type (Case 6: 1:30). The inclusion of the new cards encouraged this. She used the wild card to represent her pet lizard as the “pet cat” card didn’t represent the lizard sufficiently (Case 6; 3:30); and this card was placed on the “really happy” face on the Likert scale. She also selected a wild card to represent the rest of her animals (Case 6; 16:30). This gave some indication of the emotional link she had with her pets.

Child 8 demonstrated repeatedly the importance of pets in her life in the Likert Scale and Fruit Tree Exercises (Case 8; 37:50). The “pet” cards were also used by children to refer to contact they had with pets which were not their own (Case 9; 11:40; Case 10; 9:20). The impact that these animals have on children should not be underestimated. Although Child 9’s pet dog did not stay with her, she placed it and the “cat” card (Case 9; 11:40) at the top of the scale.

Using the Likert Scaling Exercise, Child 13 talked about her feelings for her cat and dog:

P: Uhuh, I miss her so much.

R: Where would you put (pet’s name.)

P: Put (pet’s name) there.

R: Oh right (pet’s name) makes you really happy/

P: Uhuh.

(Case 13; 1:50)

Later in the Accessibility Exercise she rationalises her separation from her pet by considering what the effect of its presence would be in the hospital:

P: Ma dog...only thing she’s not allowed up here.

R: And how do you feel about that?

P: It's ok. There are some kids in here who've got allergies to dogs and stuff or...or like, don't like dogs. It wouldnae be fair tae them.

(Case 13; 29:30)

Child 16 indicated that she was going to receive a pet hamster when she arrived home from hospital. She told how she was looking forward to this, although she would have preferred a dog. She selected the dog picture to represent the pet she was anticipating even when offered the wild card. I felt she was making a point to her mother who was present:

R: Ok, and you're getting a hamster and why are you getting a hamster?

P: Because we wanted a dog, and we're not allowed a dog. Mum and dad are working most of the time.

R: Do you want to choose one of those to represent your fish, so the dog will be the fish, shall we do that?

P: I like the dog.

R: You like the dog; I've got a wild card would you like me to make that the fish instead?

P: I like the dog.

(Case 16; 13:00)

Such responses, evoked from the use of the cards, demonstrate the impact of separation from pets for children in hospital; this is something to be considered when examining the effects of a hospital stay on children. Some children did not have pets due to their lifestyle, or their health condition (Case 14; 14:00). Responses related to this varied from rationalisation, to regret or resignation. From this, it can be deduced that children's health conditions and their "biological" make-up are contributing factors in shaping their context.

## *2. Places in the community*

The child's view of home and community provides information about the way a child might relate to hospital surroundings. The home was often viewed as the hub for relationships; and this was quickly identified by Child 15 when I asked her who stayed in the home. This question assisted me in gaining an understanding of the make-up of the family she might refer to when the people/family cards were introduced (Case 15; 14:10).

When Child 16 thought about her home, she focused on her “home comforts”. I encouraged her to expand on this but she focused on aspects that helped her to relax and feel at home:

R: What ....do you like about inside your house when you get home?

P: Big, cosy and warm.

R: It’s nice cosy and warm, what else is there that you can think of

P: Ma computer.

R: Your computer right ok and anything else there that you like?

P : And ma TV.

R: And your TV. All your home comforts. Is that what it is?

P: Yep.

(Case 16; 12:30)

The contrast of home to hospital facilities can vary depending on the material wealth of the family. Child 9 identified why she liked home so much because of the toys and play opportunities she had:

R: What kind of things make you really happy about your home?

P: I’ve got a lot of toys... CDs and books

(Case 9; 13:20).

The familiarity of a child’s home can bring a sense of security and the thought of this can bring comfort to a child when they encounter much that is unfamiliar in their hospital stay.<sup>211</sup>

The “school” card provided information about children’s views on school work, school friendships and a mixture of other experiences. School can refer to both the hospital context and the home context and children may have different perspectives on the different experiences in the two settings. Child 6 revealed early in her interview that she had difficulty with friendships at school, yet the position of the school card on the Likert scale alerted me to other aspects of school that she enjoyed:

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<sup>211</sup>Child 11, aged 13, indicated that he liked his home but did not like it to be changed. (Case 11; (00:50)

R: so you really like school but there are wee bits you don't like about school. What bits do you really like about school?

P: doing arts and crafts and doing the language work

(Case 6; 12:00)

Child 11 also had a positive attitude to school (Case 11; 10:30), but others had mixed attitudes. Child 8 placed the school card on the middle picture in the Likert scale, revealing some ambiguity about her feelings. She enjoyed her break times but did not like the pressure of hard work:

P: Then you don't, like get so much pressure and stuff like that when you are doing the work, cos, see when they give you like multiplication; I know I've already passed that now. I'm on harder multiplications so I kind a like playtimes better than doing maths.

(Case 8; 13:50)

Child 9 and 10 also expressed uncertainties about school in relation to school work and experiences of friendships. Being in hospital seemed to add to Child 9's concerns as a result of having to catch up with missed work (Case 9; 2:20). Child 13 enjoyed the social dimension of school, but did not like the work (Case 13; 2:50). In the Fruit Tree Exercise, she referred to the possible inclusion of the school card saying; "it is important but I don't want it on"<sup>212</sup>, (Case 13; 31:10). Child 16 placed the "school" card in the middle because she liked her friends at school and disliked the work (Case 16; 3:40). However, she had a positive experience of school in the hospital with the arts and crafts teacher. Child 16 brought out an item that she had made and proudly placed on the table during the interview (Case 16; 4:40).

Some children had a more negative view of their educational experience. Child 12 did not like school, placing the card at the bottom of the Likert scale. Even when asked about other aspects of school, such as friends, he still did not move the card. He was not forthcoming with reasons and described school as "annoying" (Case 12; 3:30). Child 12 viewed playing on his computer as providing a sense of reward after completing his school work (Case 12; 24:00). Such information might suggest that educational support be offered to this boy who

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<sup>212</sup> "on" refers to the board.

might be noncompliant or unmotivated in his school work while in hospital, and his hospital stay could be an opportunity to engender a more positive attitude to learning. He appeared reluctant or unable to articulate his feelings about school when he resorted to saying: “I don’t know. I just don’t like it.” (Case 12; 3:20).

Gleaning information about children’s attitudes to school may prove to be useful for the teachers employed by the council who staff the on-site hospital education. The multiple function of schools in the community contrasts with the hospital setting, where contact with peers is reduced. This may reduce the motivation of children to learn in a healthcare setting, or provide opportunities for learning for those children who struggle with relationships with peers in the school setting outside of the hospital.

### *3. Activities*

Numerous activities (see Appendix 9) were featured on the sorting cards, including holidays, shopping and sport; many of which would not be relevant in a healthcare context. However, some referred to activities which children could experience at home or in hospital. The activity cards serve as a reminder of the adjustments that children have to make to the more restrictive hospital context.<sup>213</sup> However, the activities provided in the healthcare context form the focus of this section. The way children enter into the hospital based activities represented offers insight into how they perceive the hospital setting and at what level they wish to connect with it. This section looks at crafts and drawing, watching television, reading, music and personal entertainment systems.

#### *a. Crafts and drawing*

One of the cards depicted crafts and drawing (see picture in Appendix 9); an activity that is accessible to children in the hospital. This card was given more attention by children than many of the other personal activities. The crafts and drawing card, and other activity-based cards, prompted responses that revealed children’s sense of inadequacy in some areas (Child 8 for example (Case 8; 28:30)). The assessor needs to be aware of how a child might respond to the activity cards, so as to avoid a child’s self-esteem being affected. There is a danger that some interests and activities could highlight what the children feel they are not good at.

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<sup>213</sup>It would be interesting to explore the level of impact for a child who returns home but cannot have access to such activities because of their health condition.

Child 15 enjoyed craftwork and it was a source of affirmation from her gran:

P: I like drawing and shading in... I've got a big horse thing and you had to shade in the right colours and I've done that now and my gran says I'm really good at it.

(Case 13; 4:10)

The craft and drawing card could be related to many contexts, including the hospital setting, and was therefore a card that was immediately relevant. The use of this card encouraged exploration of concepts such as hope and determination; and one child even proudly presented a model she had made when the relevant card was introduced during the interview. It appears that an activity can be associated with affirmation or discouragement.

#### *b. Television*

Watching television takes place both in and out of the hospital context. However, a number of children stated that they liked cartoons and cartoon TV networks which were not available in the hospital except by using DVDs<sup>214</sup> (Case 7; 11:00; Case 8; 13:20; Case 12; 4:20; Case 16; 3:20). Child 11, a 13-year old boy, and Child 13, a 13-year old girl, liked watching television and it was noticeable that their programme taste was different to that of the younger children (Case 13; 7:20). This can cause difficulties in a ward setting where some children may not be able to watch the programmes which would be their form of relaxation at home. As a result, children may experience issues of negotiation and adjustment while in hospital and the TV may serve as a reminder of the greater freedom they would have if they were at home.

This was highlighted by Child 12 who considered TV to be an important part of his life in hospital (Case 12; 24:00). During the Accessibility Exercise, Child 13 indicated that she could watch more television in hospital than at home because she did not need to share the television with the rest of the family (Case 13; 26:10). This may have been due to her being in an isolation room with a television for her own use, rather than in the six-bed areas which share one television.

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<sup>214</sup>What wasn't explored was the reason for investment by the parents into such television services. Was this due to compensation by the parents for a debilitating illness of the child, affluence or mere preference?

Television may be therapeutic and compensate for the boredom and inaction of the hospital day. Child 14 indicated that watching TV was not that important to him at home, but that its importance increased in hospital because “there’s not really much else to do” (Case 14; 10:20)<sup>215</sup>. Once again, in Child 11’s case, humour was a strong element in his viewing:

P: It’s just something I do when I’m tired and I find that very relaxing.

R: Is that right, what are your favourite programmes then?

P: Scrubs

R: Scrubs ok and why do you like Scrubs so much?

P: Because it’s funny and that.

R: Ok, is hospital anything like Scrubs?

P: No.

(Case 11; 3:10)

Child 15, an 11-year old girl, identified EastEnders, a BBC soap opera, as her favourite programme. I explored if there was a favourite character and she indicated that she identified with someone who was “cheeky” (Case 15: 1:20). Such discussion might give an insight into the values or qualities that children admire or the emotions they wish to experience. Using the TV card enabled these various dimensions to be explored with the children, and indicated the adjustment required from home viewing to hospital viewing. It might also provide the possibility to discuss the character and plots of programmes to find out how the children relate to them. The importance of watching television reflects the nature of the hospital setting where ways of passing time might be needed, and it may distract them from unpleasant experiences.

### *c. Reading, music and personal entertainment systems*

Other activities involving reading, listening to music or playing computer games were also accessible to the children in the hospital. Some children were conscious of the disparity between what they were used to experiencing outside the hospital, and others had no interest in them and so did not focus on these cards.

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<sup>215</sup> The way a child watches television may in Rossiter’s view diminish or enhance their resourcefulness, (Rossiter, 1997, p.28; Rossiter, 1999, p.212 )

Child 11's love of reading allowed him to adopt a strategy which passed the time in hospital. He had brought many books to be prepared for a long hospital stay:

P: ... if it was really boring in here and I had to just sit about all day.

R: And can you read all the time?

P: Yeah.

(Case 11; 9:40)

This strategy for passing the time was similar to that of children bringing in personal entertainment systems such as MP3s and Sony PSPs for a similar purpose (Case 11; 3:00; Case 14; 5:30). Child 13 described how listening to music compensated for times when she felt she was doing nothing. However, she placed this card in the middle of the Likert scale, along with the absence of friends. Child 11 had his own games on his Sony PSP which he could access whenever he wanted to.<sup>216</sup> While some activities were provided by the hospital, having their own equipment means that children can be active agents, shaping their own environment; suggesting that such an element of control may make the new context become more familiar. Children who had been in hospital before were aware of the need to bring in resources to combat inactivity, isolation and boredom.

While some children were positive towards reading, others were not. Child 12, a 10-year old boy, put the reading card at the lower end of the Likert scale and when pressed, indicated that he did not really read at all (Case 12; 6:00). However, in the Fruit Tree Exercise he selected reading as a means to build up his confidence (Case 12; 24:00). This affirming aspect was also touched on in Case 14. When the computer game card emerged from the pack, there was an immediate laugh. Placing the card at the top of the Likert Scale highlighted its importance, and his body language and response highlighted the extent of that importance. Perhaps it provided a sense of personal achievement:

P: Ha-ha that probably does need to go to the top.

R: Why do you have to laugh at that? Is it pretty obvious or what is it?

P: It's quite obvious

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<sup>216</sup> His PSP was clearly important to him as indicated by his response in the Likert Scaling Exercise (Case 11; 8:30).

R: Why, tell us more?

P: Well, I, when I was younger I went on a big gaming session thing, did quite well in it and that is when I sort of got started and really...I've not got much to do most of the time. I go on my X-Box really.

R: And what kind of things do you like on your X-Box? Tell us more?

P: Oh it's the fact that sort of you can go online and talk to other people and then the way you sort of can relieve stress in a manner.

R: Uhuh

P: Uhuh ma little brother's playing and annoy me sometimes I go on the X-Box just to relieve a bit of stress.

R: Does that work for you here?

P: Yeah but ma X-Box sort of cheers me up in here

(Case 14; 7:50).

For Child 14, playing his X-Box helped him to relax. The social dimension of his life was addressed through online interaction with a wider community. In the hospital context it helped him to have a positive attitude<sup>217</sup>. Erikson's work on social development is relevant here; the child seeks to be industrious in hospital where he is largely inactive and uses the X-box as a means to affirm his own sense of identity amongst his peers. Despite the circumstances this child faces, in terms of Erikson's theory, he has not been adversely affected. Through the choice and purpose of activity he shows the positive social development features which Erikson would have anticipated; maintaining a strong sense of identity and remaining active.

#### *4. The Healthcare Environment*

The children's healthcare environment is mediated through how staff engage with them; through the experiences they may have undergone, be those interventions such as injections; or through the boredom of waiting for full recovery or further medical tests. These experiences inform and influence how children connect to the environment and build up a perception of their surroundings. Sharing of information on the links between these

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<sup>217</sup> Some of these activities are technology based and there is a continual shift in the use of such hardware. The use of a laptop computer with a dongle enables children to have access to the internet and increases the opportunity for social networks and keeping in contact with friends. This was an area that was not touched upon by this study but in the context in which I work I have seen these being used by children.

experiences, and the children's connection with and perception of their environment, was encouraged by using pictures of the connecting points that the child experiences while in hospital.

The sorting cards included medical picture cards of a cannula, a nurse, a doctor/consultant and a hospital building. During the Likert Scaling Exercise, the "bed" card came to mean the hospital bed. The wild card allowed for other aspects related to the hospital to be introduced by the child. The significance of the medical cards is evident from Case 12 with the introduction of the question, "what really matters most to you when you are in hospital?" in the Fruit Tree Exercise. Seven out of the nine cases from Case 12 onwards included at least one hospital-related card in the Fruit Tree Exercise with five of the seven choosing three or more (See Appendix 9).

*a. The general impact of the healthcare journey on the child.*

Some of the children made broad comments about their healthcare. Child 6 said "I don't really like the hospital" (Case 6; 7:20). Child 9, when shown the card depicting the hospital, expressed a sense of unease and nervousness about coming to hospital:

R: There's a picture of the hospital when they come in. Where would you put that?

    Hmm you're not too sure. You're a wee bit happy about the nurse but you're not too sure about the hospital. Why is that?

P: Cos you get a funny feeling when you go into the hospital.

R: Do you, what does that funny feeling feel like?

P: You get a sore tummy and stuff.

(Case 9; 14:40)

In contrast, Child 10 and 14 had a positive attitude to the hospital and a clear understanding of his needs being met by the hospital. When asked about the hospital card, Child 10's answer pointed to the purpose it fulfilled for him:<sup>218</sup>

R: Here is a picture of a hospital. I think it is the entrance to our hospital. Where would that go?

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<sup>218</sup>What was noticeable with this child, up until this point in the interview, was that he had not placed a single card in the bottom two faces of the Likert scale.

P: It would go there.

R: It would go there... it makes you a wee bit happy and why is that?

P: If I was feeling sore, I'd feel happy because I was... I know they were going to fix me

(Case 10; 16:00)

When Child 13 was shown the hospital picture, she thought specifically of "jags". The picture prompted specific detail of the child's experience of hospital:

R: I've got some more pictures here of the hospital, you can tell me where you want to put them. That's a picture of the hospital.

P: Oh that looks like Yorkhill.

R: It does, doesn't it?

P: Really sad

R: Really sad?

P: Cos they make you jags and stuff but once you're settled in you'll be ok but...

R: Right.

P: When this (*cannula*) falls out it will just be back to there again.

(Case 13; 20:30)

The child initially placed the hospital card at the bottom of the scale, but moved it up one place to reflect her experience that, once she was settled, it was not as bad as at first. She moved the card when she saw the "cannula" card which she placed at the bottom of the Likert scale.

In the Fruit Tree Exercise with Child 13, the importance of the hospital and the care it offered was evident when she selected all the hospital cards first. She did not remove any of them during the exercise:

R: What really matters to you the most when you are in the hospital?

P: I would be really sick if it wasn't for them. That really matters because they need to be here to put them (pills) in and stuff. The nurses have to be here to check my ops...and to look after me

R: Um, just go through them and put them to the side. If you want to put in there you tell me.

P: The hospital because I have to stay in the hospital.

(Case 13; 29:40)

During the Likert Scaling Exercise with Child 15, she indicated her mixed feelings of relief and fear when she was in hospital; she was relieved to be treated to make her feel better, but felt fear about the unpleasant procedures involved:

“Well when I see a hospital it makes me feel no very happy. Happy because I’m safe, I’m in getting my leg like and that done but in the same way it makes me feel a bit scared as well because of my operations.”

(Case 15; 17:20)

Child 16 answered in an objective and detached way about what she thought of the hospital in general. She placed the card in the middle, representing the extremes of feeling that some children may experience. However, the negative example was drawn from her own experience:

R: the picture of the hospital?

P: In-between.

R: In-between. That’s where it should be...or sometimes you’re really happy or sometimes you are really sad?

P: In between cos sometimes in here for something nice like just for a check-up or something. Sometimes you can be in here for very bad, broken bones.

(Case 16; 22:30)

Chapter 5 described the introduction of the hospital themed cards, which provided the children with a means to share about their hospital experience explicitly, and show how they connected with the hospital. Some understood the purpose of the hospital as being wider than their own specific treatment, whilst the form of connection for others was related to the specific interventions they had experienced. Some of the medical items on the cards received more attention than others. These specialised cards allowed children to connect to their context at the level they wanted, and showed how they constructed their awareness in relation to their surroundings.

*b. The hospital bed*

Using the hospital bed card (see picture in Appendix 9) enabled children to express some of the physical stresses they experienced in hospital. Child 6 indicated her dislike of the hospital bed compounded by the need to be there because she was tired:

R: Right ok....staying in your bed?

P: (places it on the “little” sad face)

R: That makes you a wee bit sad.

P: Not really sad. Just want to get up and out and have fun.

R: How do you feel staying in a hospital bed then?

P: Don't like it. I only go to bed when I feel really, really tired.

(Case 6; 13:40)

Child 8 also experienced tiredness as a result of a disrupted night's sleep. He wanted to determine the time of day that the bed picture referred to:

R: What about staying in bed or being in bed?

P: Uhuh I haven't got any sleep in the hospital because...see that wee boy over there ... he's got his leg kind of thingyed up and he doesn't like it and he's screaming and everything and I haven't got any sleep since he's started screaming.

(Case 8; 27:00)

While Child 11 indicated, through the Likert Scale, a distinct dislike for being in bed, he rationalized his stay in his hospital bed as a change from the normal routine. However, his preference at home was to be active. So his behaviour in the hospital context differed from home. He had a chronic condition which required repeated visits, so perhaps the adjustments he needed to make were less than some of the other children had to make as he was familiar with hospital staff and clinical procedures etc (Case 11; 3:50).

For Child 12, being in bed was not a negative experience. He placed the bed at the top of the Likert Scale:

R: what about this (*hospital*) bed here?

P: Cos like, I lie in it all day. I get bed so when I get hame I just lie in my bed all day... at weekends I get up early in the morning. On school days, I just wannae sleep.

(Case 12; 14:00)

In my annotations on Child 12, I query what kind of lifestyle this child had to cause such tiredness? What was the impact of how he related to others because of his tiredness; particularly how he related to his friends? Tiredness seemed to affect his attitude towards school and how he felt after returning from school.

Child 14 indicated, through the Likert scale, a more positive view of his hospital bed compared to his bed at home; since all that he would want was immediately accessible:

R: Here's more things about the hospital, your bed, it could be your bed at home, your bed here. You can decide and where you want that to go.

P: Probably the bed here and the bed at home would probably be in the middle.

R: Why?

P: Cos I'm not really in ma bed that much at home. It's since I've hurt ma legs...its' like that I've been in bed a bit and then here, really, it's like not really anywhere else to go. It's like all ma stuffs in here so when I'm in this room in ma bed I'm sort of with, with ma stuff.

(Case 14; 16:10)

Child 10 remarked positively about how comfortable his hospital bed was and how it helped him sleep better (Case 10; 9:00). Child 16 immediately put this card to the bottom of the Likert Scale. The interview highlighted the drastic, but necessary, measures needed for her recovery and how she had to process her emotions:

P: I don't like staying in ma bed. I'd rather be up and about ...

R: See when you were told when you had to be in this bed for...how long were you told you would be in bed for?

P: Two months.

R: Two months. When you heard that how did you feel when you heard that?

P: I wanted to cry ...

R: What happened later on that day did you start thinking about it a bit more?

P: Yeah, I started getting mad.

R: And when you get mad what do you do? ...

P: I moan

R: You moan and what else do you do?

P: Shout

(Case 16; 20:00)

When the bed card was interpreted as being a hospital bed there was a mixed response; some appreciated the relaxation while others resented the change.

*c. The cannula and other procedures*

When the picture of a hand with a cannula was shown to the children (see picture in Appendix 9) all the children knew what it represented except one. Child 8 was shown the picture during the Likert Scaling Exercise:

R: Have you ever had a thing in like that?

P: Yeah, I've had that.

R: How does that make you feel?

P: They've try to take to take blood from it but...but it hasn't worked.

R: How does that make you feel when you see that picture?

P: I don't really like it the way that it is taped to your hand

R: so where shall we put it here? This one here the really sad one.

P: Uhuh

(Case 8; 7:00>>)

Child 8 placed the hospital picture at the bottom of the Likert scale:

R: And why have you put [the hospital picture] down there?

P: I really don't like hospitals and getting operations and all that stuff in hospital ...

See how the way I'm getting my operation and that see how that mask thing you've got what do you call that? Drinking the stuff that is in it. I absolutely hate that...

R: ... is your mum with is your gran with you when it happens

P: My gran goes with me for every operation I've had...

P: ... they force you to take it and I don't like it and I've been getting drips

(Case 8; 10:00)

Child 9 described how she felt when she had to get a cannula:

P: I don't like getting needles in anything

R: Have you ever had a needle before.

P: Uhuh.

R: What's it like?

P: It's sore!

R: ... .. How do you feel inside when you get something like that?

P: A bit nervous

R: ...what do you think about when you have these things happen to you?

P: Scared.

(Case 9; 15:00)

Child 10 did not seem at all perturbed by the picture of the cannula and placed it in the middle of the Likert scale. What seemed to make a difference was the presence of both parents during the cannula insertion procedure:

R: You'd put it there. You're not too bad about that?

P: Not really

R: Is that right and how can you feel ok about that?

P: It has happened to me earlier and now it's gone away and I didn't really feel a thing.

R: And you didn't really feel a thing, how did it feel when it went in?

P: Not really that bad.

R: Is that right? What did you think just before it did happen?

P: I felt a wee bit scared about it.

R: Did you, right and who was with you when it happened?

P: My mum and my dad.

R: And did that help you?

P: Yeah

(Case 10; 15:40).

Child 11 had a chronic condition which meant he was familiar with medical interventions. He was aware of the measures taken to ease the pain and, as a result, showed no sign of anxiety:

P: I did get it taken every week. Now it is every three months.

R: How did you feel at the beginning when you had that?

P: It didn't really bother me cos I've got this cream I put on; it numbs it.

R: Ok and how do you feel about it now compared to the beginning?

P: It is much easier now.

(Case 11; 19:00).

Child 12 was a trauma patient, but he portrayed a very matter-of-fact approach in describing his experience of pain. He seemed to want me to know that he was a tough individual, showing the different places cannulas were put and saying, "I need to take the pain."<sup>219</sup> While his words conveyed calm, if not casual, dismissal, he placed the card at the bottom position on the Likert Scale Exercise, indicating a strong dislike. He seemed to be connecting to a sense of 'bravado' from his cultural background when trying to impress me with the numerous locations of where he had a cannula put in:

P: I had one in there ...

P: and I had another one in there ...

P: you can see my vein pop out ...

P: it was so sore in there ...

P: it gets sore when it's took out ...

R: What do you do to get you through that time when it's really sore, how do you feel strong inside to get through that?

P: Nothing. It's just tough luck. I need to take the pain

(Case 12; 14:40)

Child 13's response to the picture of the cannula was a sharp intake of breath. It caused her to re-evaluate her previous positioning of the card with the picture of the hospital building, so that the cannula could be positioned as the worst of all the hospital cards. Child 13 described how her experience of cannulas had changed through the years of attending hospital:

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<sup>219</sup>There was no indication in the interview itself but I did wonder if this was a phrase he inherited and used to describe how he coped with his experience.

P: It's ok once you're settled in but that is really bad ... it's not as sore, I don't really cry anymore, I used to when I was a wee girl ... a bit scared just before they get it set up and all that. I'm a bit nervous but once there in I'm fine once they've put it in that's me I'm fine

R: So how do you make yourself feel strong inside?

P: Think of happy stuff ... I just pretend I'm not getting it ... You can still feel a wee nick but no as bad when I was a wee girl I used to ask them and watch everything ... I used to get myself in a big big state.

R: Did you right, what makes you happy, what are happy thoughts ... if you had happy thoughts?

P: Ma dog, ma friends and that

(Case 13; 21:00)

She used her mind to connect with feel-good aspects of other contexts of her life and through this process she was able to engage more positively with what was happening to her.

Child 14 was unemotional about such interventions (Case 14; 17:30), indicating the importance they had for him in providing treatment:

R: You put some of the things, for instance, even a thing that you didn't really like, you've got that it really matters to you.

P: Uhum,

R: Can you tell me a bit more about that?

P: It depends on what's going to happen with the medication in the lines and stuff and what's going to really happen, like, what I'm going to get done, like lumbar punctures and bone marrow.

(Case 14; 26:50)

In the Fruit Tree Exercise, Child 15 put the cannula as what mattered to her most while she was in hospital:

P: Can I put down a cannula cos, then, it matters to me. I like it getting it done, but I don't like getting it done.

R: ...why does it matter to you?

P: Because ... because ... it matters to me because I'm scared of getting it in but it goes in fine if you know what ah mean ... so will I put that down?

R: Yeah you can, is it because you know you need the medicine?

R: Yeah.

P: I know I need it and I need to get it done – scared to get it done as well

(Case 15; 29:50)

The cannula card provided a prompt to understand how children connected to the context of their treatment. This connection contained the pain, anxiety and distress children experience when having a cannula inserted. Some children had strong negative responses while others viewed it as an uncomfortable but necessary procedure. Some had reached the point where they detached their dislike of cannulas from the staff that administered them, instead making a connection to the possibility of a better life as a result of the treatment.

*d. The social impact of hospital admission*

Using the sorting cards, the children were provided with an opportunity to share the impact that their health, treatment and care could have on the social dimension of their lives. Child 8 enjoyed sports but, currently, was unable to be involved because of her plaster casts (Case 8: 17:00). Her incapacity was accentuated by the loss of this social dimension of her life.

Child 7 expressed her feelings when I introduced the card showing a bed:

R: What's it like staying in your hospital bed?

P: (she moves it to really sad)

R: Oh right. Why do you move it down, did you think of your bed at home first?

P: (nods)

R: And why have you moved it down to there? What don't you like? ... What makes you sad or very sad about your hospital bed?

P: I don't like to stay in myself.

R: ... Does that sometimes happen?

P: Yeah

R: Ok, how do you feel inside when you are in by yourself?

P: Sad.

(Case 7; 12:20)

This was the first time in this interview that any card had been placed in the bottom category of the Likert scale. This interview was conducted at the child's bedside, which was in a cubicle separated from other beds. The feeling of isolation was compounded when she was also left in bed on her own. Child 7 was asked at the end of the Accessibility Exercise what she felt about having her family visiting her. She said that she felt okay (Case 7; 20:00). While the information might be minimal, it did show that family members were still able to engender a social dimension in their visits.

The children were aware of the impact of their illness on the routine aspects of their lives. This may be an area for a healthcare chaplain to address as the children imagine the contexts they might wish to return to when recovered.

*e. Staff*

During the Fruit Tree Exercise, Child 12 was the first to be asked “what really matters most when you are in hospital?” He responded by selecting nurses and doctors and the role they play in his care and treatment. This was an aspect which had not featured in any of the previous interviews:

P: The nurses always check on you... so do the doctors, make sure they give you the medicine at the right time.

(Case 12; 24:00)

Adding this question sharpened the focus of the tool to reveal significant insight into children's views of the hospital staff, and how they play a part in the construction of the children's context and the connectedness they experience within it.

*(i) Nurses*

Child 8's response to the picture of a nurse showed she had an uncertain view of a nurse's role. Having being very talkative throughout the interview, she became much quieter.<sup>220</sup> She placed the card in the middle to indicate her uncertainty about her view of the nurse's role as being “good” and “bad”:

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<sup>220</sup> There is a need to allow silence to happen during an interview in order to understand what is meant by it, (Berryman, 1999, p.262)

P: No, can't decide if it is good or bad ... the good thing is they help me but the bad thing ... they're making me have a lot of pain and take loads and loads of medicine ...

R: ... what do you mean by bad things?

P: As in, see, how they lift me up, they don't just lift me up gently. They lift me up, see, when they try to pull me to slide me round ... that operation is kind of getting pulled and it's sore ... and they are giving me loads of medicine ... and see how before they were giving me medicine that I didn't even need so that is what bad things I mean ...

(Case 8; 8:30)

Child 10 confessed that he had not really thought about nurses or doctors enough to have feelings either way and so placed them both in the middle of the Likert Scale (Case 10; 16:30). Child 11 was more positive, indicating that they appreciated the help offered by the nurses (Case 11; 19:30). Child 12 focussed on the picture of the nurse where the person was writing on a clipboard; he interpreted the writing as his discharge from hospital. This may have been a clue to his focus on home and how he viewed the role of these professionals in relation to it. I did explore further and it seemed that having some 'banter' with the nurses was something he appreciated:

R: Picture of a nurse... so they keep you a wee bit happy?

P: Hmm. It's because she's writing down something telling me I can go home.

R: Oh right, is that why, ok. Any other reasons why you would put the nurse there?

P: Cos I like nurses.

R: What makes you want to like them?

P: Cos you can get a laugh with them.

R: Can you, right? Does that really help?

P: (nod)

(Case 12; 15:30)

During the Likert Scaling Exercise, Child 15 immediately identified a particular nurse and placed her at the top of the scale:

P: They make me feel happy and it's (nurse's name)...with the blond hair... because she is always dead cheery and stuff.

(Case 15; 18:20)

This was the first time in the project that a specific staff member was identified. This particular nurse had a positive effect on the child, and a positive effect on how she perceived nurses in general. In the Accessibility Exercise, she referred to some of the interaction she had with the nurses:

R: I sing in hospital

R: Oh do you? Do you keep everyone awake when you do that?

P: No, but the nurses get me to do it all the time.

(Case 15; 23:00)

Child 16 thought positively about the nurses in terms of how they behaved towards her:

P: They come in and chat to you and kind of not moany.

(Case 16; 18:40)

The nurse card encouraged the children to describe their view of nurses and the impact this interaction had on them. It revealed the potentially ambiguous relationship the children have with nurses as a result of their experiences. This information may help staff to address issues that children have to cope with when dealing with hospital personnel. The positive responses referred to the kind, pleasant, humorous way in which some nurses related to the children<sup>221</sup>.

#### *(ii) Consultant or Doctor*

The children showed less ambiguous attitudes to consultants than to nurses. During the Likert Scaling Exercise, Child 8 gave the consultant a higher level than any other hospital-related card because “he is fixing her”; what did “fixing” mean to her? In my annotation, I consider this by noting that it was an; “interesting description about her own sense of identity ... words, like normal or perfect. Are these words used by her or other people?”:

P: He’s helping to fix me, there.

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<sup>221</sup> Ross in her earlier work identifies how nurses may observe spiritual need but not feel able to respond to it nor have the resources to address it (1994, p.446). She elaborates further how this can be resolved, (Ross, 1997, p.39 )

R: Put it there ok and what other things does (consultants name) make you feel good?  
How does he do that?

P: Well he makes me feel good cause he's fixing me and everything and then like he's helping me so like that I'm perfect and everything just look like normal people would be.

(Case 8; 12:00)

I named her particular consultant in the question to enable the child to have a point of focus. She deliberated and considered before finalising her assessment of him. In her comments, it seemed that she was trying to connect to a perception of what “normal” or even “perfect” is. It is not apparent how this concept originated, but she had a clear idea of the goal of her treatment. Healthcare staff should consider seriously such information for two reasons. Firstly, the assessment affirms the child's right<sup>222</sup> to decide about her treatment and health. Secondly, ascertaining the source of the child's choice of words such as “perfect” and “normal” during the assessment may give insight into the psychological dimension of the child in relation to how she understands her identity in the world. The outcome of that consultation may determine the extent of treatment offered to the child and how robust her motivation was at the point of the assessment.

Child 9 expressed fairly positive feelings about both nurses and doctors due to the purpose they fulfil, as did Child 14, particularly as the doctor made him aware of his progress and treatment (Case 14; 17:10). While Child 11 regarded his consultant positively, I was aware that there was a little hesitancy before he placed the card on the Likert Scale. When I explored the reason for this, it emerged that he struggled with some of the decisions concerning his treatment:

... it's just I put him there because sometimes he make decisions that I don't want but  
... usually it is better for me

(Case 11; 19:40).

Child 12 understood the responsibility which consultants have in the care they provide. The child knew that in the early stages of his illness, the consultant's decisions were a matter of life and death. His attitude towards them was affected by what they could do for him:

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<sup>222</sup> United nations Convention on the rights of the child 1979

P: I like doctors they make you better ... they can bring you back to life if you pass away ...

R: When you say 'pass away' is that like you mean when you die or when you go to sleep when you're knocked out.

P: When you die.

(Case 12; 16:20)

Child 13 placed the picture of the consultant at the bottom of the Likert scale; the first child to express a poor opinion of a consultant. However, once we had discussed it and considered her decision, she was rather doubtful about where she should place the card, as a result of becoming aware of what the doctors did for her. While she may have changed the position on the Likert Scale, the more important aspect was what had been discovered as a result of the discussion:

P: He's always the one that tells you the bad news that you have to come in ... they're the ones that have to put the jags in.

R: Ok so you're not so happy about them?

P: I'm not terrified of them, just a bit upset when they tell me I have to come in and stuff.

R: Are they good in the way they tell you about bad news though?

P: It helps me but if it wasn't for them I would be really, really unwell ...

(Case 13; 23:20).

Child 15 had a positive view of the consultant. The focus was not on his role but on his persona and how he amused her:

P: He makes me happy, he is Mr.(-----), he is dead funny ... he just smiles a lot and laughs

(Case 15; 18:40)

Child 16 made a similar observation of her (different) consultant (Case 16; 19:20). The variety of responses to the consultant card highlighted the variety of views and the experiences that contributed to those views. While some were influenced by the professional role of the consultant, others appreciated the personal approach the consultants had with

them. The trust that some of the children show in their consultant is a sign of connectedness, even to some painful treatment. It offers a wider connectedness to a world they dream of being part of in a healthy state.

*(iii) Play Specialist*

Child 15 was the first to select the wild card to represent the play specialist. The play specialist is employed by the hospital to provide play activities. Some activities have therapeutic outcomes; others are distracting during intervention; and many are for personal entertainment. The impact they had on Child 15 was evident when the card was placed at the top of the scale:

R: Here is a picture with no picture on it but it is a wild card, so is there something that I've missed out? ...

P: Em ... the play specialist

R: ... so where would you put the play specialist

P: There, because she always gives me things to do and loads of stuff to do to keep me occupied and stuff.

R: And why is that important to you?

P: Because them I'm not sitting about bored and not knowing what to do with myself ...

R: What do you do at the weekend when she is not here?

P: She'll leave me things for the weekend, like games and things.

R: If you didn't have things like that how would you feel?

P: Sad ... I would just be sitting on ma bed or sitting on ma chair and doing nothing, basically.

(Case 15; 19: 20).

Dispelling boredom was significant for Child 15. This was evident in the Fruit Tree Exercise when she deliberately looked out this card to place it in the final slot available (Case 15; 30:30). The child viewed the play specialist as a significant connection to the hospital environment.

### **C. Discussion**

It is evident that the SAT portfolio facilitates exploration of children's experiences in hospital and facilitates a description of life from that perspective. Children have to make adjustments and judgments in response to the changes of context from home to hospital. Some changes relate to hospital specific circumstances, such as the procedures required for a child's treatment; whilst others relate to the difference between home and hospital routine, such as the support network in place for a child to feel secure and the resources available to occupy time. Certain aspects of children's everyday lives are denied to them while in hospital and these are reflected in the adjustments they need to make. It is apparent that insights can be gained into children's perspectives of the hospital, its staff, medical interventions and the general impact of the hospital setting upon their lives. The opinions prompted by the SAT portfolio are both negative and positive; some children rationalise the context they are in, while others have their general view of the hospital coloured by specific unpleasant incidents. The staff are significant for some, but not all, of the children.

This chapter is the first part of a three-stage investigation. It has demonstrated, using the data collected using the Sorting Card Exercises, that children make observations about the dyadic links which have become strained or absent, and how children respond to new contexts and form new dyadic links, such as with the hospital staff. The information gleaned from these children has helped highlight aspects of a child's life in hospital. The children's responses describe a fluid situation where considerable biological, social, emotional and relational change is experienced, and change is often expressed by comparisons to more familiar contexts, such as home.

This chapter has demonstrated that, with such a vast spread of data, a conceptual framework is required to enable a cohesive comprehensive hold to be had on the information identified. This is important in order to allow an assessor to describe the nature of images built up in children's minds and to create a picture of what is meaningful for them to share with others involved in their care. If this is to be achieved, the new concept of spirituality must describe both the nature of children's contextual (dis)connection with their admission to hospital along with the level of disruption involved. If a concept is to have the capacity and infrastructure to clearly convey the complexity of a child's spirituality in a healthcare setting, it must also be useful in ascertaining how this might manifest itself at the different stages of child

development. Such a conceptual framework will take into account a blend of the psychological developmental theories outlined in Chapter 2.

While this chapter indicates that the SAT portfolio can be used to gather information, the result of the research process has highlighted the challenge involved in managing such information, leading to consideration of the second step which is to identify and name an appropriate interpretative framework. Chapter 7 applies this framework to a case study and in doing so demonstrates how the use of the SAT portfolio can help us understand a child's spirituality in a healthcare setting.

## **Chapter 7: What can we learn about a child by applying an interpretative spirituality framework in order to understand children’s spiritual needs during their healthcare journey?**

### **A. Introduction**

Chapters 6 and 7 examine how the data gathered in this research project should be managed into a format suitable to inform a multi-disciplinary team (MDT) involved in the delivery of spiritual care. This chapter identifies a term that can suitably describe an interpretative framework to understand childhood spirituality, drawing from the child development theories discussed in Chapter 2. It presents this interpretative framework using the concept of “connectedness”, which ensures that the information gained from the SAT is clear for an assessor to communicate, and accessible to other professionals. This new concept takes cognisance of a child’s stage of development in addition to their displacement from home to the healthcare context. A case study is examined, showing how this interpretative framework can be applied. The next chapter also defines the skill set required by an assessor to manage the information gained using the SAT, by facilitating, collating and interpreting it. It also adopts the term “connectedness” to describe the encounter between the assessor and the paediatric patient.

### **B. The selection of the term “Connectedness”**

The term used to label the conceptual framework and information gathering process<sup>223</sup> is “connectedness”. The concept of connectedness draws together the interpretative framework identified using the child development theories discussed in Chapter 2. The case study discussed illustrates the process involved in applying the term and how it can carry the information to allow an assessment to be made and shared. This shows the potential of the case study to assist in the comprehensive understanding of a complex aspect of a child’s life in a clear concise and communicable manner. It is important that the term should be congruous with, and have a clear sense of affinity with, the conceptual thinking explored throughout this thesis.

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<sup>223</sup> The information gathering process is not the assessment but rather the manner in which the assessment is conducted. The way the information is gathered has to be consistent with the developmental dimensions identified in the interpretative framework so that the term “connectedness” be applied to both.

The choice of the term connectedness to refer to the conceptual framework, from many other available terms,<sup>224</sup> is significant and takes into consideration the conclusions reached in Chapter 1. The use of the term ‘connectedness’ is not merely a semantic switch to describe spirituality; it is selected to signify an image capable of describing the contextual phenomenon of children’s developmental response to their hospital experiences which may *include* what children may think of as being their spirituality.

Connectedness possesses strong physical imagery<sup>225</sup> which explains its appeal in a variety of settings be they technological<sup>226</sup>; geographical<sup>227</sup>; related to trade<sup>228</sup>; related to child development<sup>229</sup> or psychology (Cervinka, Röderer, Hefler, 2012, p.379); or to a sociological framework within an educational setting<sup>230</sup>. Connectedness is also associated with mathematics (specifically topology<sup>231</sup>), and appears in nursing<sup>232</sup> and medical journals<sup>233</sup> to describe the relationship between different environmental contexts:

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<sup>224</sup> Spirituality, well-being, holistic, transcendence. Some even speak of interconnectedness, (Carroll, 2001, p.88)

<sup>225</sup> An associated word with connectedness is connectivity and this describes how that to join two distinct entities but the connection causes them to act as one and therefore cause each to perform differently before the connection, an example of this is described in computer technology cited 10/9/12 <http://etutorials.org/Networking/wireless+community+networks/Chapter+3.+Network+Layout/3.1+Layer+1+Physical+Connectivity/>. Another term used that expresses similar physical language is “connection”. This is explained by Goldberg. (1998, p.840)

<sup>226</sup> The Human connectedness research project was part of the former Media Lab Europe. It is described in the website “The Human Connectedness research group explores the topic of human relationships and how they are mediated by technology. Our mission is to conceive a new genre of technologies and experiences that combat the effects mentioned above and allow us to build, maintain, and enhance relationships in new ways. We also aim to enable new kinds of individual bonds and communities that were not possible before but may be beneficial or fun. Cited 17<sup>th</sup> April 2012 <http://web.media.mit.edu/~stefan/hc/>

<sup>227</sup> The Distance lab was a research project that was set up to address the challenges of rural communities and how to retain links. It described itself, “Distance Lab is a creative research organisation bringing together digital media technology, design and the arts to redefine and overcome the disadvantages of distance in learning, health care, relationships, culture and other domains.” Cited 17<sup>th</sup> April 2012 <http://www.distancelab.org/>

<sup>228</sup> DHL use the term to describe the logistics of trading in the Global Connectedness Index. The purpose of this was to identify the true extent of globalisation. (Cited 17<sup>th</sup> April 2012 [http://www.dhl.com/en/about\\_us/logistics\\_insights/global\\_connectedness\\_index.html](http://www.dhl.com/en/about_us/logistics_insights/global_connectedness_index.html))

<sup>229</sup> Ensor, R., Hughes, C., 2008, Content or Connectedness? Mother–Child Talk and Early Social Understanding, *Child Development*, Volume 79, Issue 1, Pages: 201–216

<sup>230</sup> The term is used here to describe the link between the pupil and their school (Cited 17<sup>th</sup> April 2012) <http://www.cdc.gov/healthyyouth/adolescenthealth/connectedness.htm>

Sherratt, D., Donald, G. (2004) Connectedness: Developing a Shared Construction of Affect and Cognition in Children with Autism, *British Journal of Special Education* Vol.31, Issue 1, pp. 10–15

<sup>231</sup> A topological example of connectedness distinguishes topological spaces. It refers to a path-connected space, which is a space where any two points can be joined by a path. Goldman, W.M.; (1988), Topological components of spaces of representations, *Inventiones Mathematicae*, Vol.93 (3), pp.557-607

<sup>232</sup> There was reference in the term by Baldacchino and Draper, (2001, p.837)

<sup>233</sup> There is reference to sibling connectedness in Lobato DJ, Kao BT. Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *J. Pediatr. Psychol.* 2002; **27**: 711–16.

In one of the most significant works investigating the relationship between several types of influential environments (e.g., family and school) and health risk behaviours among adolescents, Resnick et al.<sup>1</sup> reported that family connectedness was significantly and inversely associated with emotional distress, suicidality, alcohol use, marijuana use, and early age of sexual intercourse. (Ackard, Neumark-Sztainer, Story, Perry, 2006, p.59)

Ackard et al. continue by saying that:

. . . the current study adds to the literature by demonstrating a significant relationship between parent–child Connectedness and a broad range of serious behavioral and emotional health risk behaviors (substance use, unhealthy weight control, suicide attempts, body dissatisfaction, low self-esteem, and depression) in a diverse sample of both boys and girls (Ackard et al., 2006, p.62).

These comments refer to ‘connectedness’ as a social indicator of what is felt by adolescents, but do not address the developmental and constructive aspect of connectedness as proposed in this thesis.<sup>234</sup> Another educational article illustrates how the term can be used in conjunction with a theoretical framework, to explain the factors involved in a pupil’s relationship with their school and how that informs the responsibility of the school to respond (Kelly, O’Flaherty, Toumbourou, Homel, Paton, White and Williams, 2012, p.438).

The range of applications of the term does not dilute its meaning, but rather demonstrates how it can be used to describe the links within conceptual structures from different fields. For instance, connectedness is used in mathematics to describe a mathematical object, such as a topological space; a graph containing related vertices, with different features but which work as one to present information in one piece. If the graph were to be broken up, the outcome would then show signs of disconnectedness. Recognising these connections enables the mathematician to identify the nature of the data and interpret its significance. What is

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<sup>234</sup> Resnick et al. offers some commentary on connectedness and how this aspect of the human being views connectedness as the “deeply felt yearning . . . between people, working to create meaning and happiness in the context of an interdependent community of human beings.” (Resnick, et al., 1993, S4)

common to these fields is that the term is applied by identifying links and considering the significance of them.

Identifying links between two points, either between the hospital and children's home or the wider community, was a theme in the previous chapter. From such identification, we can explore the presence or absence of relationships; the access, or lack of access, to offered activities; the effects of children's state of health on their ability to relate to others and themselves; and their engagement with, or disengagement from, the healthcare environment. The data has frequently pointed to the children's sense of connection and disconnection and research using the SAT has identified these links and their qualities. Therefore, the definition which I propose for connectedness is:

‘the identifying of a link, made by an individual with another person or object, in order for that individual's construction of meaning to be understood by another or themselves’.

An example relating to this definition is found in Bronfenbrenner's Bio-Ecological Theory; a theory that allowed for the identification of dyadic links between systems in a child's life. These links were referred to as connections which described the insights into what a child perceives in a healthcare context. The introduction of the term connectedness is the next step in describing the conceptual intention of this thesis, which focuses on the links made by a child to describe their perspective of their life. This will also provide insight into their spirituality as the term creates a conceptual cohesion which takes cognisance of children's stage of development, as well as their displacement from home into the healthcare context. The data highlighted in the first stage of the research, using the SAT portfolio, has provided a two-dimensional map which plots where such links are located. This chapter now addresses how the interpretative framework of connectedness is to be applied.

## **B. The application of the interpretative framework of connectedness**

### *1. The four dimensions of connectedness*

Application of the theories outlined in Chapter 2 can enable insights which contribute to a complete picture of children's sense of connectedness. The increasing number and positive nature of connections offer a robust structure which reflects the complexities of the child's connectedness. It is necessary to pinpoint these connections so that the assessor can establish

children's spirituality, as defined by their sense of connectedness. The extracts selected in Chapter 2 serve as illustrations of where each developmental theory is applicable.

The process of applying the dimensions of connectedness offers findings about the child in this case study and the multi-dimensional nature of connectedness is identified. These dimensions are used to show how the process works in reaching an assessment based on the concept of connectedness. Each of these developmental psychological perspectives contributes something to the interpretative framework of spirituality in terms of connectedness. The dimensions of connectedness identified were:

- momentum of connectedness
- resilience of connectedness
- awareness of connectedness
- evaluative nature of connectedness

*a. The momentum of connectedness*

This dimension applies the "ultimate concern" concept from Fowler's Faith Development theory. The concept of ultimate concern refers to a person's trust in how they have constructed their perception of their surrounding; it is the articulation of a person's existence. Fowler refers to the instinctive inclination of individuals to connect to their ultimate concern. This is what I refer to as "the momentum of connectedness". A child who constructs meaning defines this sense of meaning by connecting to their ultimate concern. This dimension of connectedness fuels a person's motivation to have a closer affinity with their ultimate concern, and to feel closer to achieving it. There is a belief that a person's perception of what their ultimate concern might be can be attained; the use of the word momentum signifies the energy a person is prepared to generate to reach their ultimate concern. This is understood by the person in other terms such as hope, motivation, focus, longing, desire or personal agenda. The objects of such focus could vary, whether it is a child focusing on their wish to go home from hospital, or wanting to play with friends.

The assessor would be looking for the existence of certain features such as a recurring theme, element or person; or the reason for their absence in relation to the presence of a momentum of connectedness. Fowler suggests that the coherence and direction that can be present in the circumstances of a child's life can be attributed to the self-assurance they draw from those

they trust. Coherence and direction can include a wider frame of reference such as children's communities and cultures and how they construct a sense of meaning in their lives. The momentum of connectedness relates closely to the awareness of connectedness, which is described below.

*b. The resilience of connectedness*

The resilience of connectedness focuses on the features associated with children's cognitive development and style and identifies how children are able to understand their surroundings. I refer to this as being "the resilience of connectedness". This dimension acknowledges fluctuations in a child's life experience and considers how well the child's thought patterns explore how to connect to what their ultimate concern might be. The resilience of connectedness draws from the ideas in Piaget's Cognitive Theory and, in particular, his concept of equilibrium and the possible cognitive style which helps children reach equilibrium in their thinking.<sup>235</sup>

The healthcare professional must be able to determine a child's level of development. Once this is established, the professional is better placed to assess the child's cognitive ability to construct an understanding of their current surroundings. In terms of connectedness, the ability to understand their surroundings relates to children's intellectual ability to make connections in their experience with the past and present, and in doing so, to create meaning. This is arguably most easily observable in what has been referred to as "cognitive conflict". The concept of the resilience of connectedness is supported by Bronfenbrenner's concept of "personal stimulus" and, in particular, by the term "resources" which can be applied here to the child's social and material sources. Resilience can be disguised by resources. The use of personal entertainment consoles and watching TV may also be used to such an extent as to delay a developing resilience of connectedness, as certain media narratives monopolise a child's thinking (Rossiter, 1997, p.28; Rossiter, 1999, p.212).<sup>236</sup>

It is the ability of the child to connect to other experiences and transfer and apply them to a new set of circumstances, which indicates the resilience of connectedness. The challenges to

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<sup>235</sup> In terms of development this would be the most identifiable stages.

<sup>236</sup> While there is no study of children watching TV in an excessive way in a healthcare setting. The existing habits of television watching by a child may translate into the healthcare context. The implications of that may have started at an early stage (Pagani, L. S; Fitzpatrick, C.; Barnett, T. A. and Dubow, E.; Prospective Associations Between Early Childhood Television Exposure and Academic, Psychosocial, and Physical Well-being by Middle Childhood. Archives of Pediatrics and Adolescent Medicine, 2010; Vol. 164 (5): p.425

achieve this could vary in a paediatric setting. A child with a chronic condition will draw from a greater pool of experience than a trauma patient who is new to the setting. If there was a disconnectedness to resilience, then the child may present anger, withdrawal or resistance to treatment.

*c. The awareness of connectedness*

This dimension draws from Bronfenbrenner's Bio-Ecological Theory, which offers a systemic map which shows how and where connections can be made either within individuals themselves, or by the individual within the wider setting of their life. An increasing knowledge of the individual's map offers a robust awareness of connectedness.<sup>237</sup>

It should be possible, by using the SAT, to identify the connections that have been made, retained or broken in the disruption (such as illness and hospitalisation) experienced by the child. Bronfenbrenner's systemic approach to understanding the development of the child offers another helpful framework to consider the substance and structure of a child's sense of connectedness.

It would be helpful to map out what connections are present in a child's bio-ecological framework to assist in conducting a spiritual assessment, and to provide transferable information. The bio-ecological framework for a paediatric patient is different to that of a child situated at home. Firstly, the condition of the child's health should be considered. Secondly, the paediatric patient's micro system now contains the healthcare context, which would usually be part of the mesosystem; while the child's home, usually part of his microsystem, is now part of his mesosystem. Identifying the child's understanding of this disruption of her contextual system, and how she compensates by making new connections or protecting other connections, is a required outcome for an assessor conducting a SAT. The child's connectedness has been disrupted and the contours of the child's life map have undergone a seismic shift. Those people usually present in the child's life are absent, and new people are now part of their life.

The landmarks Bronfenbrenner sets out in this systemic approach are the "molar activities" and "dyads" discussed in Chapter 2. These combine in a "joint activity dyad" and those joint

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<sup>237</sup> A SAT-NAV would be a better description as this places the individual in relation to the map. This relates to the seminal work of Joni Walton when she defines spiritual relationships and offers a map to illustrate (1996, pp.242, 246)

activity dyads in closest proximity to the child are “proximal processes.” The biological context of the individual contains further indicators which have a bearing on how the balance of influence tips between an individual and her environment. These are referred to in Chapter 2 as “demand”, “resource” and “force” and contribute to the “bi-directional influence” on a child. An assessment should identify which indicators are present, what form they take, and the extent to which the child is using them and increasing her awareness of (dis)connectedness in her life.

*d. The evaluative nature of connectedness*

While Erikson’s model has limited applicability here, it is useful inasmuch as it refers to the internal dialogue of the individual. This dimension considers the social development of children in relation to Erickson’s Social Development theory (see Chapter 2), with particular reference to the “internal developmental dialogue” which a child experiences at each stage.

If Fowler’s work is the fuel, Erikson’s stage theory acts as the refining agent which assesses the turning point in the development of a person’s life, highlighting the importance of the maintenance of an internal dialogue in enabling that turning point to be reached. Erikson’s work outlines the manner in which a child might engage with their ultimate concern. This is the evaluative nature of connectedness of an individual.

In Erikson’s theory, the interpretative framework of connectedness can be viewed through the internal dialogue associated with the stage of the child. In this case study, the interpretative framework of connectedness will be quite limited as according to Erikson, the current stage is affected by the way the child performed in the previous stages. This previous performance is hard to verify but to engage in observing the stage the child will at least show what this model can contribute to understanding a child’s connectedness while in hospital. Using Erikson’s theory in conjunction with others, offers a counter balance to offset this problem. Erikson’s concept of “crisis” may be effective in identifying when the internal developmental dialogue of each stage becomes insufficient to describe how a child understands the social dimension of life.

*2. The connection and balance between these dimensions*

This interpretative framework developed in this thesis allows for interplay between the four dimensions in a child’s connectedness, showing how each relates to and supports the others.

Conversely, it highlights the absence or depletion of any dimension which might contribute to disconnectedness. The compromise of any of the dimensions in a child's connectedness can be identified as disconnectedness where there is a loss of momentum, a lack of awareness, a reduction in resilience, or a dulling of evaluation. These aspects could interplay with each other and even compound and accentuate disconnectedness. The comparisons between these constructs highlight the issues involved but should not be seen as excluding other factors. I have chosen to highlight three dimensions to demonstrate how the connectedness between the dimensions and how they function.

When the momentum of connectedness is combined with the awareness of connectedness, there can be maintenance of, or even an increase in, momentum sustaining an awareness of connectedness. In terms of a sick child's microsystem, there is a momentum of connectedness to get better, which might also include the presence of a parent at the hospital. If a mesosystem was introduced at this point (such as the child's family, home, and school friends) this could form another level of connectedness. The level of momentum is affected by the child's belief that she can connect with their "ultimate concern". If children display an awareness of how their connectedness functions, take steps to protect it, and are successful in doing so, then the resultant outcome will be a sense of connectedness. When there is a lack of awareness or ability to connect to the ultimate concern, then disconnectedness occurs.

When the evaluative nature of connectedness (which involves a child's internal evaluative dialogue appropriate to the child's stage of development) relates to the resilience of connectedness, other features emerge. For example, it may be observed that parents will contribute to the resilience of connectedness, enabling a child to reach a settled state as the parents understand their child's developmental stage and how it relates to his or her internal evaluative dialogue. Conversely, parents who do not perform as well in contributing to the resilience of connectedness may cause frustration in their child, resulting in disconnectedness; the child is unable to reach equilibrium because the parents have hindered the process.

The last combination to be highlighted demonstrates how disconnectedness can occur when the momentum of connectedness, which is the ultimate concern of a child, is out of alignment with his or her evaluative nature of connectedness. This may be noticeable in what has been referred to as "intermediary concerns" which relate closely to the evaluative nature of

connectedness. This may be important for children who undergo repeated hospital visits and have a variety of interests or hobbies which reflect their social developmental stage. During a hospital stay, some of these interests may not be accessible to them and they may no longer be able to sustain their momentum of connectedness for an intermediary concern. For instance, in the case of one of the older children in this study, contact with friends was more important than his personal entertainment system. This would suggest that there was a transfer from an intermediary concern (passing the time in hospital) to his ultimate concern (maintaining links with friends at home).

### **C. The Case Study**

#### *1. The rationale of a case study approach*

While a case study cannot produce general conclusions, it provides an opportunity to view in detail how the design of the SAT has been developed through the series of interviews. The SAT is designed for the analysis of an individual rather than a pool of patients. The aim is to interpret a child's spirituality through the concept of connectedness.<sup>238</sup> It is my contention that the use of a single theory does not offer the depth needed in a context that has a multi-dimensional impact on the child. The case study approach is used to enable healthcare professionals to envisage more clearly how they can engage in the detailed process that requires such a level of insight.

#### *2. Case 17–The Profile*

Case 17 is a 10 year old Scottish boy I have decided to call Duncan (a pseudonym). He has been admitted repeatedly for treatment of a chronic condition, cystic fibrosis. Through the interview it is evident that he has an extensive family network which remains close to him. His religious background is Roman Catholic, but he and his parents do not practise. He lives within travelling distance from the hospital. Duncan was the only boy interviewed in Stage 3.

#### *3. Why was this case selected?*

This study involved a total of 20 interviews.<sup>239</sup> Case 17 was interviewed during the last stage of the project (as explained in Chapter 6) when the design of the SAT was more refined<sup>240</sup>.

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<sup>238</sup> The following chapter will illustrate the skill set that is needed to deliver a spiritual assessment tool for children and how that the design of a SAT needs to be complimented by an appropriately skilled healthcare professional

<sup>239</sup> See Sandelowski, 1995, p.182

The choice of this case over the others from this Stage was based on comparison rather than exclusion. The child's chronic medical condition was improved by the treatment received during his many hospital visits and this affected his view of the healthcare context. The two components of this child's illness and his experience of frequent hospital stays, provide information as to how this child addresses new experiences in a context he is familiar with. The complexity of his circumstances offers insight into how an interpretation can be drawn from the available data and, in one case, allowed the use of all the dimensions referred above. His mother was absent for part of the interview but returned during the latter part. This created a changed dynamic and also gave me the chance afterwards to discuss her observations and compare them with my own. There was no parent present during interviews with the other children. Other factors were also considered (see footnote below)<sup>241</sup>.

Duncan has been in hospital before and has acquired a good understanding of the hospital context. This has also provided him with insight into other healthcare experiences, compared to those of a child admitted after a trauma. His new experiences are accommodated in his

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<sup>240</sup> During the interview with Child 20, it became clear that while the child was in mainstream education, she required extra educational support. It would be useful to explore how to make the SAT more effective for such children but this is not the focus of this chapter.

<sup>241</sup> At 10 years old, this boy could be placed in Piaget's Concrete Operational stage (7-12) which meant that he should have the ability to think, using mental operations. The two other possible choices for the Case Study were both 7 years old. Studying a child in the middle of a cognitive stage allows a clearer focus on the design of the tool as it is less likely that the cognitive capacity of the child will be a limiting factor if any difficulties in using the SAT emerge. A 10-year old, according to Piaget, has the ability to perform certain tasks and understand why these operations work. This child should be able to understand and play the game make the required decisions in a logical way. It was evident in this interview that he felt confident enough to ask for clarity when required during the interview.

Selecting a child in the middle of the stage reduces the possibility of the occurrence of features in Piaget's theory (see chapter 3) which have been criticised, namely that he underestimated the ability of the child and that the transition between stages can be blurred. If the findings are inconsistent with the characteristics of this stage, then further consideration needs to be given to the reasons. Further study needs to be given to how well the data was gathered with the younger ages in this recruitment spectrum of 6 -13 years old. A child in the middle of this development stage may display limitations on his understanding; according to Piaget, this boy should not be able to deal with more abstract concepts, such as considering why he has a chronic condition that affects quality of life. This is not an ambiguity within the stage but should, illustrate a clear distinction with the other developmental stages.

In Erikson's social development theory, a 10-year old would be placed in the stage, Industry vs. inferiority (6 – adolescence). The discussion in Chapter 3 did raise concerns about Erikson's theory referring to the ideal development for a child. There was some suggestion that such development may be inhibited in a child with a chronic condition. This case may offer relevant data on this issue.

Since Erickson's theory is so foundational to Fowler's faith development theory, the discussion above provides a foundation to explore Fowler's "Mythic-Literal" faith theory to see if it can add insight into the connectedness of the child through the SAT.

mind by his past experience. His current hospital stay has been positive for him as the intrusive cannulas have been replaced by a central line. This has provided him with a sense of progress about this visit to hospital and he has improved more than on past visits.

#### *4. The data*

During the interview, when Duncan described his family and home, his affection for them was evident in his tone of voice, and he described his home as being “cosy”. The selection of cards related to home and family indicated that these were Duncan’s ultimate concern. He provided an amusing response to the “singing and dancing” card (see picture in Appendix 9):

R: Would you not, ok, singing and dancing?.....

P: Like when I'm getting out, I sing...

R: Ok, is it because you are happy?

P: Uhum

R: Right, ok, and you are singing away. Do you start dancing?

P: Depends where I am... if nobody sees me.

(Case 16; 13:00).

Duncan’s ultimate concern was evident when he referred to the presence of his parents in the hospital and what they did for him. For example, his dad purchased magazines for him and this provided him with a sense of connection with his dad, who although having to go to work, connected with his son who appreciated him buying a magazine.

When I presented the sorting cards representing people, I asked Duncan to decide who was of primary importance. He started to point to his nephews but when the question was put in relation to the hospital, he was quite decisive that his parents were most important. The Likert Scaling Exercise reinforced the fact that his immediate and wider family bring him happiness (Case 16; 26:00). The only slight reservation is that his brothers “annoy” him sometimes (Case 16; 27:00). Duncan was part of a large extended family. He was the youngest in his own family, but was an uncle too; the relationship with his young nephews appeared to be very significant as he described the make-up of his family<sup>242</sup>:

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<sup>242</sup> Later in the interview the boy had forgotten that he had selected a card to represent his mother and opted to use a wild card to represent her. I did remind him what he had already selected. Despite this being a lapse of memory in the task, it underlines again that his mother plays a significant role during his time in hospital. What

R: Who's important to you when you are in hospital?  
P: Ma nephews and ma brothers and ma sisters.  
R: And what about your mum and dad?  
P: They are too...  
R: And what about your grandparents  
P: And them because they sometimes come in and see me...  
R: ... Which ones are really important to you when you are in hospital?  
P: They two.  
R: Ok, they two being your mum and your dad?...  
R: You want the nephews definitely; you keep on going back to your nephews don't you? Why do you like your nephews so much?  
P: 'Cos I just love them.

(Case 16; 5:30)

The family maintained the connection they had with him by visiting and in this way his grandparents remained important to him while he was in hospital. Overall, the family were highly thought of and this was observed by the mother as we reflected on the interview (Case 16; 39:30):

R: I'm just going to ask mum, did you learn anything new about... watching this and maybe anything about Duncan?  
M: I did, yes.  
R: Could you tell me a wee bit more?  
M: He's quite a happy wee boy, just looking at his cards, family orientated as well and loves having his family around about him and he's quite happy coming into the hospital and he knows the doctors and nurses are here to help him, so he does. So it was quite good watching him doing it.

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is also significant was that this wild card was introduced after his mother had returned to the cubicle where the interview was taking place. I do not consider this to be him giving the right answers but more his concern to have remembered everything that he felt he should have in response to the question (Case 16; 21:00).

Duncan's momentum of connectedness became increasingly apparent. Duncan's activities were a stepping stone to his ultimate concern and so contributed to his momentum of connectedness. There is a plurality of function in Duncan's ultimate concern, when this is related to the different systems of Bronfenbrenner's Bio-Ecological Theory. These may be referred to as intermediary concerns that serve towards that ultimate concern. Bronfenbrenner calls them joint activity dyads. Therefore, Duncan's momentum of connectedness corresponds with his awareness of connectedness. For instance, at one level, using Playstation 2 helped him shape his microsystem and this was identified in the Likert Scaling Exercise (Case 16; 25:30). This could be considered as an ultimate concern, or an intermediary concern. It corresponds closely with what Erikson would consider in Duncan's social development as resonating positively with his internal developmental dialogue of being industrious. The assessment would be that his momentum of connectedness is focused on his family and is sustained by intermediary concerns involving his family.

However, these intermediary concerns are given priority only when they sustain his focus on his ultimate concern. The child seeks activity, whether consciously or not, to counteract the inactivity of the hospital setting. For instance, Duncan plays the Playstation 2 frequently and enjoys it, but eventually feels bored. He then stops playing. This pattern of usage is shaped by the child's nature of connectedness. If the momentum of connectedness does not address the child's social development and maintain a positive feeling for their internal developmental dialogue, then the focus of that function wanes and is replaced by something different. Indeed, what Duncan refers to as "the passing of time" alludes to a higher ultimate concern which is his home and family. He compensates for inactivity in the hospital as a result of his treatment, which, in turn, meets a higher ultimate concern, the physical condition of his body.

What is significant here is the sense of activity that this child seeks through using a Playstation 2 and how he gains a sense of significance through such activity. This was clear when he looked at the sorting cards:

P: I like reading magazines. That's passing the time too ... If I don't have a Playstation, I'd be reading a magazine.

R: So is that important to you when you are in hospital?

P: Uhuh, sometimes...

P: Uhuh, the play leader would give you stuff to do...so you're not bored, if you

get bored with your Playstation and that.

R: Ok the Playstation can kind of make it boring

P: Uhuh... yeah and too much telly cos sometimes you just get fed up the same game and all that.

(Case 16; 13:00)

The inactivity compared to the busyness of his other contexts could make Duncan conscious of his limitations, as his health condition inhibits him leading a full active life. It is apparent that there is a need for a variety of activity. Some activities have a bearing on other contexts. Other activities such as the Playstation, craft activities provided by the play specialist (Case 16; 25:50), or reading magazines help him get through this period of time which is a disconnection from his ultimate concern. This was evident in the highly positive position he gave to these activities in the Likert Scaling Exercise (Case 16:25:00).

The SAT also offered material which can be elucidated through Bronfenbrenner's Bio-Ecological Theory, concerning the microsystem of the child's context within the hospital. The play specialists act as a dyad within the hospital context, as they are a means to activity on the ward. This was also shown through the Likert Scaling Exercise where Duncan selected the wildcard to represent the play specialist (Case 16; 25:30). Duncan's "conception of the ecological environment" (Bronfenbrenner, 1979, p.9) enables him to shape and engage with his environment, to connect well in the environment and draw meaning from it through what Bronfenbrenner calls a "joint activity dyad" (Bronfenbrenner, 1979, p.210). The play specialist had a prominent place in Duncan's mind because her role displayed features consistent with what Bronfenbrenner called a dyadic link. Therefore, a stage appropriate activity could provide the momentum the child needs to have a sense of connectedness in hospital. The Playstation 2 also was a reminder of "home comforts." This meant that there was an overlap of activity from two contexts.

Another factor in Duncan's life which adds to the momentum of connectedness is his education. Educational activity whilst in hospital helps him to be as active as his usual peer group at school, providing him with a sense of purpose. A hospital stay can often mean that children fail to keep up with the educational attainment of their peers at school. The significance lies in the mesosystem, in what I refer to as his awareness of connectedness. Duncan gives priority to his education over other activities in order to serve his ultimate

concern; his ability to achieve affirms his awareness of him being well and maintaining his routine. In the Likert Scaling Exercise, when all the spaces were used up, he decided to replace the “watching television” card with the computer card, which was significant as the computer card represented educational activity (Case 16; 13:00).

Duncan is aware of the responsibilities in his other context (Case 16; 15:00). This is not the case with many children who are hesitant over the “school” card. However, he is making a strong connection that even while he is in hospital he wishes to pursue his education. In Bronfenbrenner’s bio-ecological model, this connection with his educational context serves as a dyadic link, where the child retains meaning and purpose in activities during a period where many activities are undertaken merely to pass the time. It is important to observe how he narrates the purpose involved in his educational activity in order to understand the importance he attributes to his current context. His decision to swap to the computer card in the Fruit Tree Exercise indicates that his connection to education is significant, despite his admission that he does not feel the same pleasure in this activity as he does in the more “leisure-based” ones. Eventually Duncan replaced the computer card with the schoolwork card. The computer is a dyadic link to another context enhanced by the individual’s ability to use it. Duncan is demonstrating the bi-directional influence to shape his anticipated return to school, where he will be able to continue working at the same level as his peers. The computer is a “dyadic” object that maintains the momentum of connectedness, allowing Duncan to fulfil one of his ultimate concerns, which is the advancement of his personal education.

Duncan has his own laptop computer and this is the material link that he identifies with in relation to his education. If the computer was broken or left at home, this might have a significant bearing on how he viewed his stay in hospital. It is apparent that Duncan is aware of the complexity of his environment and the decisions he makes within his microsystem, in relation to other contexts, that he is connected to. Despite Duncan’s ambivalent feelings towards education, he still understands the significance of it. If his attitude were to change, this would indicate an uncharacteristic disconnection.

Were healthcare staff able to make observations like this, it would help them to ensure that a child’s educational link was supported and protected so that the child has a clear sense that this connection has not diminished despite their absence from school. Although Duncan

considered school to be important, this did not mean that he liked school; in the Likert Scaling Exercise he placed school in the centre of the Likert scale (Case 16; 23:00).

Bronfenbrenner's theory indicates an appreciation of the "personal characteristics" of the individual and it was apparent that Duncan's temperament, motivation and persistence were influential in shaping his attitude towards education. This aspect of his "bi-directional influences" differed from that of the other children in relation to education in hospital.

One of the features of Duncan's interview was an underlying theme of cleanliness in relation to his health condition; this seemed to be a factor in Duncan's momentum of connectedness. His own biological condition was of ultimate concern. The immediacy of that ultimate concern within the child's own microsystem makes for a powerful combination in terms of Duncan's sense of connectedness, and this shaped his other contexts. His cystic fibrosis took precedence over ideas of enhancing his home context:

R: Do you have any pets?...

P: I'm not allowed so because I have cystic fibrosis...it's because of the hairs. I used to have two fish but they died.....

R: ... Are you a wee bit sad not having pets?

P: I'm not bothered. I would like a dog but I'm not bothered

(Case 16; 7:40)

This momentum of connectedness pervades all ecological systems. The biological environment of his own body takes precedence over his personal preference to have pets since this might affect his health. This momentum of connectedness has made his resilience of connectedness so robust that he has reached equilibrium over this aspect of his life. There is still a broader acceptance that Duncan needs to have, in terms of his condition and his status as a person, but this may change as he develops.

Duncan disclosed that people prayed for him, and this information raises the connection with his exosystem and macrosystem. Family members informed him of the prayers of friends and neighbours of the family. This is part of the wider cultural dimension in his macrosystem, as his family have Roman Catholic links. The significance of this macrosystem and exosystem is that his family, who are part of his micro and mesosystem, wish to communicate the comfort this brings. This increases the dyadic role of the family by showing that they care;

these acts of prayer through the lighting of candles are seen as symbols of comfort to Duncan. This concentrates the focus of one of his primary ultimate concerns, which is the security and closeness of his family as shown in the Fruit Tree Exercise:

R: Here is a picture of a church. Is that important to you when you are in hospital?

P: Sometimes because I know old people and that, that go to church and they light candles for me.

(Case 16; 8:10)

The picture of the church was put on the happiest face in the Likert Scaling Exercise because people from the church were thinking about him (Case 16; 25:00). Further conversation with Duncan revealed that he did not pray at home or in hospital, but only as part of the school ritual of prayers. However, this discussion did allow us to explore why he was in hospital:

R: ...has there been any thoughts inside your head when you've thinking about being in hospital about why you are here?

P: Uhuh

R: What kind of thoughts do you have?

P: Just because I was born with cystic fibrosis and then I had to keep getting cannulas and they kept falling out during the night and I got a port-a-cath.

R: And that port-a-cath has changed things for you?

P: Uhuh.

R: And because you've got that port-a-cath you don't think about all those other thoughts when you had the cannulas?

P: Em, uhuh.

(Case 16; 39:30)

This discussion indicates the focus of Duncan's momentum of connectedness which was the condition of his body and the treatment he has experienced to improve and maintain his quality of life. It underlines the critical importance of cleanliness in this child's microsystem. The messages of comfort conveyed by religious and local communities who focus their concern on Duncan's health, act as a "dyadic" link to the community. This is something very important to him.

During the use of the hospital storyboard later in the interview, Duncan introduced the “church” card and, in conversation, I was able to establish how he was aware of the connections he makes:

P: And then people lit candles in church

R: Do they do that when you are in hospital?

P: Uhuh don't they?

R: How did you find that out?

P: Because they told ma dad that they were going to do it... eh it's somebody doon the road from mae and she works in the chemist and then the person that's next door tae her.

R: How does that make you feel inside?

P: Good that people dae that.

(Case 16; 35:00)

This momentum of connectedness was evident too, in his selection of the travel cards, showing the importance of the car in relation to his stay in hospital (Case 16; 10:00). The car makes home more accessible to the hospital and a child's awareness of this can bring a sense of connectedness to other contexts:

R: What... are they important to you when you are in hospital?

P: The car is sometimes... because it takes me in and out from mae house.

R: Ok...other ones....are they as important as the car?

P: No...

R: Do you want to put the car on the tree?

P: Uhuh, em, ma papa, swap.

R: We'll put papa here and we'll put the car there.

(Case 16; 10:00).

Duncan was prepared to swap his grandfather card with the car card because of the importance of the latter. A dilemma was avoided by putting the people cards together so they could all remain on the board. I felt as an assessor that it would be premature to dispense with these cards as it would diminish the opportunity for further insight into objects such as the

car, which was a means of connection.<sup>243</sup> It is another dyadic object which increased Duncan's resilience of connectedness and ensured that his momentum of connectedness was not diminished. The importance of the car was reinforced in the Likert Scaling Exercise when he placed it on the "little bit happy" face. This suggests that, while he is in hospital, his thoughts are for his home and family, but when he is at home, his focus is on the accessibility of the place of treatment.

When Duncan was presented with the "playing with friends" card, he viewed it in terms of the surrounding healthcare context (Case 16; 12:00). This highlighted his ability to adapt to a new context and his ability to influence his context. However, in my reflection on this point, I found it hard to understand how a child with cystic fibrosis, who is isolated in a cubicle, would be able to have access to other children in the hospital:

R: Ok playing with friends ...is that important to you when you are in hospital?

P: Sometimes and company and that in the ward...uhuh, right, like the bed bay it's like company sometimes...

R: So, is that important to you when you are in hospital?

P: Not that much.

It emerged from discussion during the Likert Scaling Exercise that Duncan's approach to friendship or friends was positive but that they were not an essential part of his life<sup>244</sup> (Case 16; 25:00). The dynamic played out in relation to this is similar to the function of the Playstation 2; his attitude to friendships reflected his stage in social development. Duncan's construction of meaning during his hospital stay is being constantly addressed by this dimension of connectedness that evaluates the significance of meaning in relation to his social development; what is referred to as the evaluative nature of connectedness.

There are other conflicting aspects within the healthcare journey where the momentum of connectedness can clash with this evaluative nature of connectedness. It is important to ascertain whether Duncan's connectedness is resilient enough to handle this cognitive

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<sup>243</sup> The car enabled Duncan's family to have him home on day pass. He was able to enjoy the benefits of home but also return to the hospital for his medication.

<sup>244</sup> It is possible that due to his condition and large family that friends are not a dominant feature of his life at this time. This could change and may affect how he relates to the hospital if friendship became an important part of his life.

conflict. The first card shown to Duncan showed a picture of a cannula. He was quite familiar with this apparatus and its name and he had had many experiences of its use:

R: So obviously this is what it was like at the beginning. It is to do with your port-a-catheter just now. Is your port-a-cath important to you when you are in hospital just now?

P: Uhuh.

R: So would you swap it with anything on here?

P: Mmm the Playstation2.

R: The Playstation 2; so it is more important than that... ok?

(Case 16; 16:30)

In the healthcare context, Duncan's priorities change. The Playstation card takes priority over the television card. His treatment takes precedence over his Playstation. When he was shown the television card, he had interpreted it in terms of his Playstation. This underlines the importance he attributes to the cannula card which represents his port-a-cath.<sup>245</sup> During the Likert Scaling Exercise, when he saw the cannula card, he was unsure whether it should represent a cannula or a port-a-cath. He stated how he was really pleased with his port-a-cath but would have placed the card at the saddest face if it had represented the cannula (Case 16; 25:00). While this child might be hesitant in answers, as stated earlier, at this point he was able to speak with confidence and speed, displaying a knowledge of how and why his port-a-cath works (Case 16; 18:00)<sup>246</sup>.

As a cystic fibrosis patient Duncan is acutely aware that while he is able to be away from the hospital on day pass, his medication timetable requires him to return at the right time for treatment. At one point in the interview, the discussion focused on his proximity to the

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<sup>245</sup> "A Port-a-cath is a small medical device inserted beneath the skin. The port is connected to the vein with a use of a catheter. It has a septum where blood samples can be drawn and through which medications can be administered. For cystic fibrosis patients having a port-a-cath means medical personnel can have constant access to the person's veins to draw blood or to administer antibiotics.

"Port-a-cath is a term derived from "portal" and "catheter". Normal catheters are usually implanted in cystic fibrosis patients when they need IV antibiotic therapy. The problem with regular catheter is that they need to be removed when the patient leaves the hospital. A port-a-cath is inserted only once and stays permanently on the patient. In the medical field, these catheters are usually called a central venous access device."(cited 22/2/11 at <http://www.aboutcysticfibrosis.com/portacathportacathportacath.htm>)

<sup>246</sup> What would be of interest to develop is to see if Duncan's momentum of connectedness shifts back from healthcare matters to dyadic objects associated with his home.

hospital. The importance of that was based on his knowledge that he required easy access to medication:

R: ... now why is that important that you come back to the hospital?

P: ...so I can get ma medicines in time.

(Case 16: 19:00)

The phrase “in time” describes more than the location of the hospital where he receives his medication. Duncan wishes to optimize his time at home, but he also wants to ensure that he does not endanger his health by being late for his scheduled medicines. This balance is only possible due to the close proximity of his home to the hospital. There is a contrast between being conscious of getting to the hospital on time and the experience of “passing of time” once in hospital. The change of context from one system to another, moving from an exosystem to a mesosystem and then again to a microsystem, seems to affect the child’s consciousness of the chronosystem. It is not only the sense of time, but the comparison of experience of time which emerged during this interview.<sup>247</sup> This comparison of experience is particularly noticeable in this case, as Duncan has had a chronic condition from birth. The experience of a child in hospital for the first time, perhaps due to a trauma, might give rise to a different perception. This connection to the chronosystem shows the scope of Duncan’s awareness of connectedness. Duncan is able to make more of a comparison between the start of his treatment a couple of years ago to the current time, especially since there has been a noticeable improvement in his condition resulting in less need for intrusive treatment than before.<sup>248</sup> The improvement in the method of delivery of Duncan’s treatment allows him to draw from the resilience of connectedness, as this corresponds to equilibrium compatible with adding to his momentum of connectedness, which allows him to centre his microsystem on the context of his choice.

During the Fruit Tree Exercise, the importance of the medical and nursing staff was

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<sup>247</sup> It is interesting that children with chronic conditions or those with repeated visits prepare themselves with resources to cope with “passing the time”

<sup>248</sup> I am unaware if these improvements are due to the advancements within the treatment offered to the condition in general or if this is a natural development for the individual. This could be significant. If it is part of a general clinical advancement then this is a factor that emerges out of the exosystem of the child, who is unaware of the developments in medicine but if that was brought to the attention of the child this would be a positive connection to make. If it is an improvement in his individual care this is more a connection with his mesosystem and how he relates to his actual treatment and not the perceived possibilities

considered in order to examine what type of connectedness Duncan had with his mesosystem, and how that was maintained through the dyadic links with healthcare staff who represent that context. In the Likert Scaling Exercise, he indicated the staff made him “really” happy by how they related to him (Case 16; 23:30). I took the chance, when the interview was interrupted by a physiotherapist, to remind the child of the wider staff network. This brought an acknowledgement but nothing more (Case 18; 20:00). However, during the Likert Scaling Exercise the doctor and nurse cards were placed at the top, and Duncan was hesitant about the wild card representing the physiotherapist. It appeared that this was because of the nature of the treatment given by the physiotherapist. His subdued tone of voice also reflected his feelings:

R: Put that one down slightly lower?

P: They make you work hard down at the gym.

(Case 16; 24:00)

At this point, I introduced a wild card<sup>249</sup> in order to broaden his perspective of people he came into contact with, other than doctors and nurses:

R: Couple more wild cards. Is there anything else that I've forgotten?

P: Mmm, like the cleaner ... they clean our room

R: And are they important to you?

P: Uhuh because it keeps all the dust, they keep all the dust away.

(Case 16; 21:00)

What happens in the healthcare context around Duncan has significance for him when seen from the perspective of his own state of health. The defining feature of his own microsystem, which is the good state of his health, is how he connects and interprets his surroundings. He refers to it in concrete terms (see section on Piaget in Chapter 2) by mentioning the cleaner. The condition of his hospital cubicle is important to him as would be the state of his home. The interaction with a cleaner could be what Bronfenbrenner describes as a “joint activity dyad”. The presence and performance of the cleaner reinforces one of the criteria which

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<sup>249</sup>In my annotations I noted that “the child was a bit dumbfounded by this term that his tone of voice changes completely as if he comes out of character. 14/9/09 It was as if he was whispering to find out what he needs before we could proceed. This did make me consider whether the child had entered into a role play with this interview and wished to perform at his best and that with my support at this point of the question he could continue in such a mode.

affirm Duncan's ultimate concern; to preserve the quality of his health. In the Likert Scaling Exercise, he indicated that the cleaner made him 'slightly happy'. The interaction through the SAT identified how Duncan's awareness of the context he is in is defined by his own health condition, which is important to his sense of connectedness. The reassurance that this is taken seriously by the hospital sends a positive message to him.

This was reinforced when Duncan interrupted the flow of the story. The key players had been introduced and a plot developed up to the point where the physiotherapist would get rid of the "crackle" in his breathing<sup>250</sup>:

P: The physio would come and see me.

R: Ok right, why is the physio really important to you when you are in hospital?

P: Em because it will make ma crackles go away ...

(Case 16; 32:00)

While home is a reference point for the construction of the story, Duncan views contexts outside the home in terms of any possible threat to his vulnerable health. This relates to Bronfenbrenner's idea of the child's body as a context. Duncan wished to reframe the story to include this dimension of his life.

Bronfenbrenner's bio-ecological systemic model offers further insight into how the connection with other contexts or "systems" is defined by the predominant feature of Duncan's own microsystem, which is the health of his body. There are channels or connections in Duncan's mind that are primarily made in order to preserve his health. If these are affirmed, there is security and confidence in his surroundings:

R: Right ok, is home really important to you while you are in hospital?

P: Em, no.

R: No, its not?

P: A wee bit.

R: In what way is it a wee bit important when you are in hospital?<sup>251</sup>

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<sup>250</sup>Crackles are respiratory sounds made by obstructions such as secretions in the lungs which is a symptom of cystic fibrosis.

P: To make sure it doesn't get in a mess and that.

(Case 16; 2:00)

When Duncan narrates his story, he increases the momentum of connectedness when he acknowledges how those who offer treatment take an interest in what he considers to be an ultimate concern. This relates closely to another ultimate concern, already identified above, which is his interest in ensuring his own quality of health. His story, at this point, blends these two ultimate concerns. The dyadic links to these ultimate concerns are his family and the medical staff. It is not just the clinical achievements of the staff, but also the nature of their dyadic link that enhances Duncan's sense of connectedness. Duncan indicated how the medical staff took the time to ask about his home and family. This interest shown by staff for his family is appreciated by Duncan. The affinity between these two groups of people strengthens his confidence that they have a common goal, which is for him to achieve his ultimate concern to maintain his health in order to enjoy being with his family at home. This is what Duncan wishes to relay through the narrative he selected for the story.

In Duncan's story, the child's hospital visit is for the purpose of flushing the port-a-cath. I combined some of the findings of the previous exercises to examine significant aspects in the child's perception of the hospital staff and how they make him happy. It is not just pain-free treatment that is important, but also the connection the staff make with him:

P: Uhuh its' just a needle they put in...and it's a wee tube they put medicine in it.

R: And they do all these sorts of things and they still make you feel happy?

P: Uhuh cos it isn't sore

R: Is it because they fix it or is because they are nice people? What kind of people are they like?

P: They're nice and they talk to you...and when they talk to you sometimes it can makes you feel happy...

R: What kind of things do they talk to you about?

P: Like they just talk to you about your family.

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<sup>251</sup> The interaction here is important. The annotation from this part of the interview, which is highlighted in blue is as follows, "I felt I was compensating for the child's perception of the card. I thought he perceived in a very physical way in his initial response but my approach of intervening paid off as it revealed what the child thought about home and what was special about the home. In the development of the tool I felt I needed to ask this since the exercise about the home and the hospital is absent in this process However I'm unsure if I'm influencing the child unduly but I still felt it enabled the child to say more. 21/9/09

In showing an interest in Duncan and what matters to him, the staff make a connection with what lies at the centre of how he constructs meaning.

While the above data reveals Duncan's ultimate concerns, there are intermediary concerns which reflect his internal developmental dialogue and provide a measure of his connectedness within his current healthcare context. This raises the profile of his evaluative nature of connectedness. The boy's story contained a flurry of medical activity and accounts of meeting people involved in his treatment. I then asked him what he would do during the remaining two weeks of his stay in hospital. His hand moved to the series of activity cards that were left<sup>252</sup> (Case 16; 33:00). He used the reading card to represent a magazine<sup>253</sup>, and he integrated the activity cards by saying that there were drawing activities in the magazine he had been bought by his dad. I asked him what he would like to draw but it emerged that he would draw "hangman" which was a game he played with his mum. These activities were significant as they were closely related to the key people in his life; his parents. Each parent had played some incidental part in the story until now, but played a significant role in offering a familiar context at various levels that relate to his momentum of connectedness. At the end of the story I asked him a question which revealed that point:

R: Out of all those are there two that are the most important to you when you are in hospital?

P: Ma mum and ma dad...because they help me. Ah might be sick and the nurse isn't there, they'll run and get me a sick bucket.

R: So they help you when you are feeling down.

P: And they bring me sweets up.

This evaluative nature of connectedness is maintained in the way the healthcare staff address this two week period; they keep Duncan's momentum of connectedness high by allowing him

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<sup>252</sup> He used all the cards except the healthy eating card because he felt there was nothing to say about the card.

<sup>253</sup> I was able to know what type of magazine he would like by finding out that it was either "Simpsons" or wrestling magazine (Case 16; 34:00). This would be helpful information to help staff engage at a level where he is interested. "Simpsons" is the title for an animated satirical commentary of life through the routines of an American family by that name. Available from [www.thesimpsons.com](http://www.thesimpsons.com) accessed 10/7/12.

a day pass to go home, which serves to maintain a good equilibrium for Duncan's connectedness. This explains why the house card in the story (see picture in Appendix 9) is used in the healthcare journey. Duncan is an inpatient but can go home during the day and play with his friends (Case 16; 34:30). The two cards selected depicted his home, and him playing with his friends. He focused on family activity, such as seeing his grandparents, brothers, sisters and nephews, around the home whilst on a day pass (Case 16; 36:00). He described this as "good" (Case 16; 35:00) and I was curious to know what that meant:

P: And then ma big sister will come over and see me, ma two big sisters and then I'll see ma nephews.

R: See your nephews, how does that make you feel inside?

P: Good

R: What kind of good?...

P: Because I love them.

(Case 16; 35:00)

The annotation records, "He speaks about love to describe what it means to be with them 21/9/09". The boy's tone of voice changes as he sounds warm and affectionate as he shares this information with me and I can sense the emotion of what he says.

## **5. What assessment can be made of Duncan in this process?**

The assessment below is shaped by the dimensions of connectedness described at the start of this chapter and draws from the combinations of dimensions also highlighted.

### *a. Momentum of Connectedness*

Based on Fowler's theory, Duncan is in the mythic-literal stage. This highlights the characteristics of his ultimate concern and how the momentum of connectedness presents itself. That Duncan is in the mythic-literal stage can be observed from the way Duncan presents his story and the impact that his story has on him. He narrated the attainment of his ultimate concern, apparent, for instance, in the priority given to the cleaner being at the start of his story. This identified one of his ultimate concerns as having a healthy body, showing how his connectedness is maintained and disconnectedness avoided. It is evident that the momentum of connectedness is sustained considerably by the presence of his parents and their involvement during his hospital stay. Their support is dyadic in nature as they are a

close link to other “systems” in his life. The result of this is an awareness of connectedness which remains acute. This enables Duncan to have a robust connectedness, where momentum and awareness collude to provide him with the strength he needs.

*b. Awareness of Connectedness*

The mapping out of Duncan’s awareness of connectedness due to his admission to hospital reveals a disruption to his bio-ecological framework. The micro system now contains the healthcare context which would usually be part of the mesosystem, and the child’s home is now part of his mesosystem. This disruption also includes an accentuated awareness of his biological context and how that relates to his new surroundings. The dyadic links and activities put in place, particularly by his parents, compensate positively for this unsettling time and enable Duncan to maintain his momentum of connectedness, with his ultimate and intermediary concerns.

*c. Resilience of Connectedness*

Duncan displayed a resilience of connectedness during his interview and this was underlined by the equilibrium he was able to demonstrate. Duncan was “trying to make sense of his world so he is better able to understand it and engage with it” (Chapter 2). He has reached equilibrium by drawing on previous experience. At this point in his healthcare journey, Duncan has a resilient cognitive style and there is no cognitive conflict. In Duncan’s case, his ability to rationalise events, and the significance he attributes to these events, reveals his cognitive capacity to make connections which make his current context meaningful.

*d. Evaluating Nature of Connectedness*

In terms of social development, Duncan is in the stage described as “Industry vs. inferiority”. Based on Erikson’s theory, three prior stages have shaped Duncan’s present stage; although his condition will have had a bearing on those stages, meaning that Duncan may be atypical for this stage. It is evident that he is maintaining a good level of internal dialogue through activities appropriate for his stage. These include the use of a laptop computer, educational activities, Playstation games, magazines and television; activities which make him feel busy. Some of them are sustained by dyadic links and molar activities, which show the overlap of this dimension and the awareness of connectedness. This would lead to a further strengthening of his sense of connectedness.

*e. Summary of above assessment*

The data gathered through the use of the SAT suggests that Duncan has a strong sense of connectedness. He has an extensive awareness of connectedness which is maintained by dyadic links and joint molar activities. It seems that the positive effect of the treatment means it is relatively straightforward for him to maintain a resilience of connectedness. This has not been the case in the past, and this state may be challenged if his condition were to deteriorate. This would become evident if two key factors which carry his momentum of connectedness were compromised; contact with his family, which includes the prospect of going home; and the quality of his health. There are other intermediary concerns relating to Duncan's hospital stay, which relate to certain activities he participates in such as watching TV and playing computer games. These have been identified through the evaluative nature of connectedness of Duncan's internal developmental dialogue. His sense of connectedness is strengthened further by the presence of his parents engaging with these activities and healthcare staff showing an interest in his family. The SAT has identified that Duncan has a robust sense of connectedness and suggests how that infrastructure is shaped, how it needs to be protected and where it might be compromised if circumstances were to change.

**6. The child's own assessment of the interview**

Duncan's assessment of the interview was revealing in terms of how he described other activities during the interview. The SAT results appeared to be consistent with the child's evaluative nature of connectedness, as there was a clear correspondence with his internal developmental dialogue. Activities "passed the time" (Case 16; 38:00) and this appealed to his industrious nature, while also reinforcing other earlier internal developmental dialogues such as his identity.<sup>254</sup>

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<sup>254</sup> When we reviewed the three activities, Duncan indicated that he liked the story board best (Case 16; 37:30). He had thought it was going to be hard but found the process "easy". This would suggest that the length of time taken was not an issue for Duncan. He did say that the Fruit Tree Exercise felt long. This was understandable as it took up 22 of the 43 minutes of the whole interview. He didn't feel tired or physically uncomfortable sitting in one place for the whole time:

P: It was just good you can do this sort of thing in hospital.

R: And do you think it will help me know you better?

P: Uhuh

R: Do you think it would help your stay when you are in hospital that people knew all about you?

P: Uhum, so they don't need to keep asking me the same questions all the time.

(Case 16; 39:00).

## **7. Conclusion**

The choice of the term “connectedness” relates well to the data gathered in this and previous chapters. The term is appropriate in describing the disruptive circumstances experienced by a paediatric patient. It supports the conclusions of Chapter 1, where the need was established for a neutral term which brings cohesion to the interpretative framework emerging from the study of the child development theories outlined in Chapter 2. The use of a case study offers necessary insight into how the interpretative framework of connectedness can be used with a child; and highlights how the four main components of resilience, momentum, evaluation and awareness can offer the necessary insights for healthcare staff to understand the needs of the children in their care. It enabled an exploration of how the four dimensions interrelate and an assessment of how robust a child’s connectedness is. However, for these interviews to achieve the goal of gathering data, it is clear that certain skills are required by the researcher. The skill set required by the assessor is identified and described in Chapter 8.

## **Chapter 8: What insights have been gained into this tool and its development to indicate the competences required by a healthcare professional to conduct the SAT in an appropriate way with a child in hospital?**

### **A. Introduction**

The management of the data obtained from the SAT requires two measures for the effective transfer of information. The first was addressed in the previous chapter by applying the cohesive term “connectedness” to an interpretative framework which can clearly explain children’s perceptions of their life during a healthcare journey. The second measure will identify the skill set of an assessor to allow children to share information about themselves. This chapter will explore the competences required by an assessor to enable successful use of the SAT. The chapter outlines the required general foundational competences required for SAT administration, and then focuses in more detail on the specific skill-set required for conducting the SAT portfolio in a paediatric setting.

This chapter builds upon the conclusions of Chapter 3, with particular reference to Myer’s application of Ritual Process Theory in combination with Vygotski’s ZPD, exploring how these theories can be applied to the concept of connectedness to explore if the resultant concept can extend to describe how an assessor and a child relate to each other within the Zone of Proximal Connectedness (ZPC). Reference is made to data taken from interviews with children that most clearly reveal the skill-set required. The general and specific skill sets bring together the competency model being used to professionalise healthcare chaplaincy (Mowat, 2008, p.56; Mitchell, 2003, p.13; Swinton, 2008, p.5 Aldridge, 2006, p.19) and developmental psychology to identify the specific skills needed for conducting a SAT. The process of engagement with the child using the SAT is what sociologist, Christensen, refers to as the “dialogical enterprise”. She states:

I suggest that my readiness to join in with and respect the communicative forms of children established a reciprocity between us and thus created a route for them to enter into a dialogue with me about my particular questions, interests and ways of communicating.  
(2004, p.170)

The interviews with children in this research project give much needed insight into healthcare chaplaincy competences which are not merely based on professional peer agreement, but also

on interaction with children. In so doing, this research process identifies these skills in a reflective manner, in order not to overlook or assume the basis of this skill-set.

As part of this reflexive<sup>255</sup> process, it is important to note that the concept of connectedness provides a broad and professionally accessible language to describe a child's spirituality. It should not be assumed that the skills to conduct the SAT are, or should be, exclusive to a healthcare chaplain. I make reference to the competences promoted by healthcare chaplaincy professional bodies because, as a researcher, these competences are a part of my work and I wish to avoid any assumption about my own presumed skill base. Reference is made to these foundational competences not as an argument for the exclusive right of chaplains to make an assessment, but rather to identify the essential skills required.

### **B. Stage 1: The professional basis of the SAT competences required**

The basis of discussion on a specific skill-set for the use of a SAT emerges from the existing basic competences identified by professional healthcare chaplaincy bodies. In the UK context, the publication, *Capabilities and Competences*, enables a better understanding of the contextual parameters that the detail of the skill-set identified in this thesis fall within (NHS NES, 2008)<sup>256</sup>. This publication contains general statements that indicate that if working with children, a healthcare chaplain requires knowledge of child development<sup>257</sup> to function effectively. However, more detailed identification is required of the core skills needed for the ZPC to function properly.

Capability 1 in the *Capabilities and Competences* document addresses the knowledge and skills required for professional practice indicating that a chaplain should “continually [develop] and [update] his or her knowledge of spiritual and religious care, current policy, and research evidence relevant to chaplaincy services, and [use] this to promote and develop effective, evidenced based practice” (1.1, NHS NES, 2008, p.10). In this thesis, evidence from practice is offered to meet the requirements of spiritual and religious assessment and

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<sup>255</sup> In social theory this is a conscious process of reflection by the person acting. In the case of this thesis, it is the researcher being aware of how their involvement may affect the research they are conducting.

<sup>256</sup> NHS Education Scotland website, *Spiritual and Religious Care Capabilities and Competences for Healthcare Chaplains* webpage, Available from: <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/spiritual-care/about-spiritual-care/publications/spiritual-and-religious-care-capabilities-and-competences-for-healthcare-chaplains.aspx>, [Accessed: 9/7/12]

<sup>257</sup> At this current time there is no child development modules designed for healthcare chaplains involved in a paediatric setting. This is a competency that requires attention not just for the conducting an assessment but for engaging children generally.

intervention. Until now there has been no research into the implications of child development on the delivery of healthcare chaplaincy in the UK, and yet there are NHS chaplains employed to deliver spiritual care in paediatric hospitals (See Chapter 1).

The second capability (1.2) refers to ethical practice, stating that “The chaplain maintains and develops his or her knowledge of culture, diversity, ethical, professional and legal theory and frameworks. This knowledge is used to support interactions with individuals using the chaplaincy services” (NHS NES, 2008, p.14). An associated competency (1.2.2) relates to any assessment tool where the chaplain is able to “differentiate personal beliefs, morals and values from healthcare ethics” through the process of internalised assessment (NHS NES, 2008, p.12; Austin, 2006, p.541; LaRocca-Pitts, 2004, p.20). The chaplain’s self-awareness of their ability to reflect on practice is important and has been developed, applied and evidenced in this study through journaling, documenting annotations in Nvivo and writing reflective position papers.<sup>258</sup> A specific example is given in relation to the competency (1.2.3) where it states that the chaplain should “provide an ethical, theological and pastoral resource to engage with individuals and the institution” by “supporting individuals facing the ethical and theological implications of their situation” (NHS NES, 2008, p.14)<sup>259</sup>. Therefore, this chapter explores how it is that when an interpretative framework of connectedness is applied using a ZPC, it provides the assessor with the internalised means of engagement between himself and the competences required for a ZPC to occur. This acts as a reflective tool to ensure the skills are being applied during the assessment.

Capability (1.3) addresses communication skills. The chaplain is expected to “[develop] and [maintain] the communication skills necessary for the spiritual and religious care of individuals and groups” (NHS NES, 2008, p.13). The demonstration of these competences to meet the capabilities relate to what is involved in the assessment tool used in this study, as the tool requires “active listening” and “open questioning” by an assessor when a paediatric patient shares information on a one-to-one basis. Competences (1.3.1) and (1.3.3) both

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<sup>258</sup> These have been referred to through this thesis. A journal was kept to document ideas and development of thought. The annotations were footnote comments facility in the Nvivo software used to for the verbatims. A reflective position paper is referred to in this chapter concerning a challenging time while studying for my PhD (Burnard, 1991, p.464; Mays and Pope 2000, p.51).

<sup>259</sup> The dilemma has been that these competences are not merely being sought by healthcare chaplains but also the nursing profession (Heilferty, 2004, p.274). There is a need for collaboration other wise there is duplication or streamlining of services.

require communication skills in pastoral care settings and highlight what is expected from a chaplain who is conducting a SAT<sup>260</sup>.

The United Kingdom Chaplaincy Competences Framework does not explicitly address working with children (NHS NES, 2008, p.7). Additionally, the field of paediatric chaplaincy is specialist and relating to children is only one part of the work encountered in paediatric chaplaincy. However, the Paediatric Chaplains Network (PCN) based in the US and Canada, has sought to address the skills required when working with children in a statement of competences on their website.<sup>261</sup> The statement is adapted from the National Association of Catholic Chaplains<sup>262</sup> and contains four sections: personal maturity, theology, pastoral care and leadership.<sup>263</sup> The PCN identifies competences which can be applied specifically to children, and not just in a paediatric setting. This helps to identify the detailed competences required to conduct a SAT such as the one documented in this thesis. However, it must be remembered that the PCN is part of North American healthcare chaplaincy which has a different training method that might require a different approach to developing appropriate competences to conduct a SAT. However, PCN does lay out specialist requirements for chaplains to work in paediatric healthcare settings.<sup>264</sup>

In the PCN competences section entitled “A. Self-knowledge and personal maturity” only one competence out of eight makes an implicit reference to children; speaking of a paediatric chaplain having to demonstrate “The ability to relate well to a wide variety of persons and age groups” (A.6).

In the section entitled, “C. Knowledge and skills in pastoral care” 17 competences make some reference to children and their world<sup>265</sup>. The knowledge and skills noted as being important include:

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<sup>260</sup> Another model available is used in the palliative care setting and is explained in Gordon and Mitchell (2004, p.647).

<sup>261</sup> [www.pediatricchaplains.org](http://www.pediatricchaplains.org). This was cited on 19<sup>th</sup> April 2011. The specific address for the competences on this website is with the following hyperlink. [http://www.pediatricchaplains.org/index\\_htm\\_files/CompetencesCompetences.htm](http://www.pediatricchaplains.org/index_htm_files/CompetencesCompetences.htm) What cannot be ignored in this material is the nature of the different training a chaplain experiences in North America compared to the United Kingdom.

<sup>262</sup> <http://www.nacc.org/resources/documents.asp>

<sup>263</sup> <http://www.nacc.org/resources/documents.asp>

<sup>264</sup> <http://www.acpe.edu/> (cited 6/3/12) provides a good summary of Clinical Pastoral Education and how this is an educational training programme for spiritual care givers.

<sup>265</sup> Those that are listed here make reference to the chaplain’s awareness of the developmental aspects of childhood, the contextual factors that affect a paediatric patient and the interventionist skills when need is identified.

- An understanding of the faith development process in human beings at various ages and stages. (C.1)
- An understanding of psychosocial development, family systems, and relational dynamics. (C.3)
- An ability to translate developmental understanding into meaningful pastoral relationships with infants, children, adolescents, and adults. (C.4)
- The ability to relate pastorally to diverse forms of family units, respecting their culture and style of making decisions, offering them opportunities to express their faith in ways that are meaningful to them, and serving as a resource in responding to their own and their children's spiritual needs. (C.5)
- Skill as an advocate for the rights, responsibilities, needs, and values of paediatric patients, families, and healthcare professionals in the process of medical decision-making. (C.6)
- Skills in active listening, counselling, referral, and group leadership with children, adolescents, adult family members, and staff. (C.10)
- Crisis intervention skills with children and adults. (C.13)

These competences narrow down the context of skills required for an assessor using a SAT, and indicate that that the PCN presume that assessors (and all in the healthcare profession) will possess an understanding of the dynamics of a child's psycho-social world including family, peers, agencies and institutions, in addition to having knowledge about the cultural and religious beliefs of children (McSherry and Smith, 2007, p.18; van Leeuwen and Cusveller, 2004, p.237; Swinton and Pattison, 2010, p.235).

Some of the PCN statements could be adapted to become generic in their application if the word "child" or "children" were replaced with "patient" to refer to any age. It is clear that the focus of these competences is wider than this thesis as reference is made to a chaplain relating to "family". However, the list of competences identified above has a specific paediatric focus, where consideration is given to the "development" of the child. It is vital that an assessor possesses an understanding of child development in order to know how to gather information from a child; "an ability to translate developmental understanding into meaningful pastoral relationships ..." (C.4). This statement is a key reference point for what a professional body, like the PCN, expect a healthcare chaplain to do. The introduction of the Zone of Proximal Connectedness (ZPC) helps to identify the dynamics involved for an

assessor to make a connection with a child and create a free flow of information between them (Hyde, 2005, p.35)<sup>266</sup>.

The information from the interviews conducted for this study, and the information from the case study in Chapter 7 have helped to develop an interpretative framework of a child's sense of connectedness; gathering information from the children required particular skills, which I identified through my engagement with the children during the interviews<sup>267</sup>. The skills required are not only evident in good practice, but can also be discovered through learning from poor practice. The skill-set centres on the creation of a ZPC with the child, to identify the information drawn from the dialogue between the child and the healthcare professional. At all times, the dynamic between the child and assessor is based on "what is possible for them to say . . . and what is possible for us to hear them saying" (Aldred and Burman in Greene and Hogan (eds.), 2005, p.176).

In Chapter 3, combining Vygotski's Social Cultural Theory with Myers' use of Ritual Process Theory identified the core conditions of hospitality, liminality, reflexivity and connectedness, for an encounter to qualify as what is now termed a ZPC. This chapter will identify the competences required for the assessor to create an encounter which might deliver a successful interaction with a child and provide an environment conducive to the use of the SAT portfolio in a paediatric setting.<sup>268</sup>

The parameters of the skill-set in the ZPC are understood through Bronfenbrenner's concept of proximal process, where the assessor is able to enter the child's microsystem and be part of that child's immediate environment. The assessor must have an affinity with the child in order to be considered by them as having a dyadic quality which helps them relate to each other. The assessor must be familiar with, and confident in using, the SAT so that the interview situation is comfortable for the child. The application of the SAT is a proximal

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<sup>266</sup> This is what is referred to by Gadamer as the middle space.

<sup>267</sup> "it was evident that my communication with children did not benefit from an accessible understanding of the different stage elements of child development. When I studied this aspect more it provided that momentum for change through my reflections entered into the annotations for the transcription in the Nvivo software." 7<sup>th</sup> July 2009, reflexive paper

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1. a healthcare chaplain offers a hospitable space
2. A healthcare chaplain's interaction with a child should help a child recognise they are with someone of experience allowing the child to feel safe and secure during an assessment. Sometimes referred to as "liminality".
3. A healthcare chaplain has the role as a mentor, coach, or a teacher.
4. The healthcare chaplain engenders an environment where a child believes that the sharing of information with the assessor is consistent with the manner in which they construct their sense of meaning.

process and, for the purposes of this thesis, it is argued that when the assessor adopts the principles of the ZPC, this will encourage successful connection with the child. The combination of tool and assessor skill is necessary to achieve good results.

### **C. Stage 2: Establishing the Core SAT Competences**

Four core conditions were identified as being important to the creation of a ZPC with a child. These core conditions assist in identifying the main skill-set needed to successfully use a SAT. Firstly, the assessor must ensure the creation of a hospitable space. There must be a clear focal point for the encounter so that children feel part of it and sense that they are safe. The creation of this hospitable space is enabled by what I refer to as “hospitality skills”.

Secondly, there is an experience of assessment, where the assessor creates a momentum which allows children to share. This is referred to as a liminal space where the assessor facilitates the children’s exploration of their environment through the visual triggers being presented, and through the stories they are encouraged to develop. This process is more than facilitating; it allows children to enter the hospitable space and live in the experience of the encounter. At one level, assessor and child are both allowing themselves to be part of the story or to be absorbed in the event of storytelling. The assessor must possess liminal skill to enable this to take place.

Thirdly, the assessor must be aware of their role as an adult seeking to appreciate the child’s understanding of the environment, to avoid transferring adult assumptions when interpreting the information the child shares while still being able to reflexively understand the perceptions of the child (this ties in closely with the momentum of connectedness).<sup>269</sup> This is known as reflexive skill. The fourth core condition is to allow the child to reach a point where the SAT becomes a dyadic link connected to what has been referred to as the child’s ultimate or intermediary concerns. The assessor should be aware that the information and connection that is being made is the child’s self-disclosure of his momentum of connectedness. The event of the assessment is connected to the child’s ultimate concern. The information shared by the child is a statement of trust or, at least, implies a perception that the information given might help the healthcare team to appreciate the child’s connectedness and so be sensitive to any needs that become evident. This ability to identify the extent of the child’s connectedness

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<sup>269</sup> In terms of nursing Sawatzky and Pesut speak of a transcendent awareness that refers to a nurses ability to understand a patient’s “ability to make meaning of their circumstances” (2005, p.24).

is called connectedness skill. If these four aspects of an assessor's skill-set are present then the assessor can be said to possess "an ability to translate developmental understanding into meaningful pastoral relationships with ... children."<sup>270</sup> For the purposes of this thesis, an understanding of the interpretative framework of connectedness is also needed.

The pursuit to make a SAT whose design and interpretative framework incorporates child development theories, places the onus on the assessor to have at least a basic understanding of child development theory. The outcome of the SAT should be that the assessor is able to relate the findings to a child's spirituality and religion (Davies et al., 2002, p.62; Dell and Josephson, 2006, p.181; PCN, n.d.). This knowledge base serves as the foundation for the appropriate application of the ZPC. Without this knowledge, the characteristics of this encounter between the assessor and a child would be compromised. It was important, for instance, to be able to place Duncan (see Case Study in Chapter 7) in the concrete and formal-operational stage of development, as defined by Piaget. When Duncan was shown a card representing home, he focused, initially, on the concrete significance of home; the tidiness and the place for his possessions. He did not consider other aspects of his home as of immediate importance to his stay in hospital, but when questioned further he used the abstract idea of "cosy" to relate to his home; this captured why his home was important to him when he was in hospital:

R: What kind of things do you think about when you are at home? When you think about home what kind of things do you think about?

P: Cosy.

(Case 17; 2:50)

An understanding of Piaget's concept of equilibrium can be used in relation to the concept of connectedness in order to understand children's ability to perceive their surroundings in linear terms, by making comparisons between past and present experiences. An understanding of Bronfenbrenner's systemic model allows the assessor to explore and understand the present experience in the current context and to see how well a child is able to imagine other contexts which are not his immediate surroundings, for instance, the child's

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<sup>270</sup> www.pediatricchaplains.org. This was cited on 19<sup>th</sup> April 2011. The specific address for the competences on this website is with the following hyperlink. [http://www.pediatricchaplains.org/index\\_html\\_files/CompetencesCompetences.htm](http://www.pediatricchaplains.org/index_html_files/CompetencesCompetences.htm)

home. This will help the assessor to ascertain how ably children can make connections which help them to reach a level of equilibrium that makes their hospital stay a positive experience. On the assumption that these competences are present, I now turn to the core conditions necessary within the encounter to ensure a successful application of the SAT.

### *1. Hospitality*

The assessor must possess hospitality skills to create an environment which enables the child to have a sense of being kept safe at every level. Myer's use of Ritual Process Theory describes how ritual elders deal with "boundary issues, assure safety and provide direction and closure" (Myers, 1997, p.83). Moore's definition of ritual elders is that they are "technicians of the sacred" (Moore, 1984, p.136). Myers likens the ritual elder to Vygotski's significant other in the way they co-construct reality or scaffolding (Myers, 1997, p.83). These terms describe the assessor's responsibility to protect and to provide a positive purposeful direction for the child.

Levels of safety include the physical, cognitive, emotional and social.<sup>271</sup> To ensure a child's physical safety, the assessor should be able to recognise any signs (communicated verbally or non-verbally) of a sick child's physical discomfort (Kelly, 2002, p.14). This may be shown by the child's responses to prompts and questions which could slow down or speed up if the child was experiencing physical discomfort. For example, in the case of Child 1, the interview process was streamlined when the child began to show signs of physical discomfort (Case 1; 31:00) as this began to affect his approach to making choices (Case 1; 32:00). After a pause to relieve his discomfort, it appeared that he struggled to focus compared to the flow he had at the start, and so I offered to stop. Hospitality skills require that an assessor be sensitive to the impact of a child's condition on their physical state.

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<sup>271</sup> These dimensions to a child's safety is an aspect that is taken seriously by the Christian community such as the Methodist Church as cited in their website page "Creating safer space", on 14<sup>th</sup> February 2012 <http://www.methodist.org.uk/index.cfm?fuseaction=churchlife.contentandcmid=3542>. While some policy measures are in place it is apparent to church leaders to readdress how a church environment could best serve children, e.g. The Bishop of Lichfield makes comment on this in relation to Good Childhood Report from the Children's Society. Cited on the web 14<sup>th</sup> February 2012, <http://www.christiantoday.com/article/church.must.provide.safe.space.for.children.says.bishop/23794.htm>

The primary responsibility for a child's safety remains with the parents and any research interview can take place only with their consent.<sup>272</sup> Similarly, an assessor cannot be entirely in control of the environment in which the interview is conducted. The assessor must be aware of how to respond to any changes, whether that be within the child or the interview environment, in order to ensure that the safety of the child is maintained at all times. The child can decide who is present during the assessment and a parent's presence can introduce certain factors which the assessor must take into consideration, as the flow of information from the child may be affected. The presence of a parent may give an increased sense of safety to children, but it may also affect the information they feel safe to share, although they may not be aware of this (Irwin and Johnson, 2005, p.827). It is not possible, or ethically desirable, to exclude parents from interviews held in an acute paediatric setting where dual consent is required and where the child may wish to have a parent present. The responsibility rests on the assessor to ensure that no undue influence is applied by parents on their children for instance, by wishing them to 'perform well' by offering suggested answers; and that the children do not use the assessment as a means to do anything other than share information about themselves.

The assessor should be aware that he cannot be drawn into comparisons and must remain detached and interfere as little as possible in the SAT activities.<sup>273</sup> For instance, Child 17 made a direct comparison between two cards each representing a family member. I felt her comments gave an unhelpful interpretation of the placing of the cards, based on her opinion of a family member, and I tried to compensate for this by reflecting back her decisions as a reference point. This was the first time that a direct comparison was made since the Likert Scaling Exercise was used after the first five cases:<sup>274</sup>

R: And your dad is there a wee bit happy?

P: Yeah.

R: Ok, why are you laughing. You need to tell me, well it would be helpful if you did. Does your dad ...

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<sup>272</sup> While this is not a skill an assessor needs to remind both parents and child that they can stop the interview at any point. This was stipulated in the research project material given to the parent and child, prior to the interview.

<sup>273</sup> This is a similar expectation of student nurses, (Kenny and Ashley 2005, p.183)

<sup>274</sup> The Likert Scaling Exercise was used to avoid causing distress due to unhelpful comparisons between aspect of a child's life where they were both valued by the child. In this case the child wanted to make a comparison to make a comment about a member of her family.

P: I like my dad better... I like my dad better than ma brother.

(Case 17, 16:00)

She then teased me and her mother (who was present) with the placing of her mother on the Likert Scale:

P: Ma mum.

R: Your mum, I know that is not her colour of hair ... are you teasing us?  
there (laughter)... good on you! So she makes you really happy?

P: Uhuh.

(Case 17; 16:40)

While this was presented in a light-hearted manner by the child, the assessor should be aware of undercurrents in family dynamics so that what is shared and the manner in which it is expressed does not affect the status of the child *vis-à-vis* the family. The assessor must be alert to the emotional impact that the content of the interview might have on the child and is responsible for the emotional stability of the child during the interview process. While none of the children in the interviews showed signs of being emotionally upset, there were issues raised which may have caused upset, such as those associated with bereavement, child protection, substance abuse and self-harm. Child 8 recounted how her grandfather had died the night before she was born and, as indicated previously, this was a story that she had inherited and incorporated as part of her own history (Case 8; 1:40). I did not explore this further as she responded in “a matter of fact” way about her deceased grandparents. Were a child to be still processing feelings about a grandparent who had died, the assessor would need to be aware of the potential impact of this, and possess the skills to handle the child’s emotional state. It may also be useful information to pass onto other staff involved in caring for the child.

An assessor must respect the boundaries set by the child and must reassure the child that any decision to withhold information will be respected. It became apparent in the interview with Child 15 (Case 15; 16:30) that she lived with her grandparents, not her parents. She gave me a reason for this, but I was aware that there were other reasons. I recorded in my annotations that I felt the child was unwilling to pursue this and so I did not feel comfortable in developing this line of questioning.

The assessor's hospitality skills are vital in helping children to feel secure about sharing information. The next part of the discussion will address the liminality of the assessment encounter.

## 2. *Liminality*

Liminality, meaning threshold,<sup>275</sup> is a key component of discussion in relation to areas of study such as psychology (Homans, 1979, p.207; Adams, 2003, p.108) and anthropology (Turner, 1995, p.ix, 95; Jennings, 1982 p.115; Prout, 1989, pp.338-339). The term is sometimes applied in metaphysical terms as a subjective state, but in relation to the immediate discussion, which draws from Myers' work and uses play and storytelling, a specific anthropological application<sup>276</sup> is more relevant.

Myers describes "liminal space" as being related to the creation of regular set activities and events, such as arranged eating times for a group of children being supervised by adults, so that boundaries such as personal safety are maintained. Within that event there is conformity to an expected pattern and as such a child and an adult conducting that event, by playing a game or rehearsing a story together, would create a liminal space between them where each would conform to the rules of the game or the structure in telling the story. This may not be a daily occurrence, but there would still be a cultural expectation that such play activity would encourage conformity of response. For instance, in Engel's investigations into storytelling she refers to a "cooling function" which would be a means to master or control the feelings and experience that may have had control over the child in the past (Engel, 1995, p.40). Play has ritual characteristics which involve role play and therefore have the capacity to create liminal space.<sup>277</sup> The tools used in this study involve role play and to be used effectively the assessor must possess skills to ensure the creation of liminal space, through the use of the role play tools, to ensure a safe environment for the child. These skills are referred to as "liminal skills".

If an assessor is aware of this contextual dynamic in relation to the stage of development of a child, it would enable them to appreciate the child's perceptions and to engage with the child in play and storytelling that is appropriate to the child's liminal role. The assessor would

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<sup>275</sup> This is taken from the Latin.

<sup>276</sup> Ditto

<sup>277</sup> Ditto

understand the need to take a child-centred approach that enabled the child to express feelings, beliefs and values that would be shared during this Zone of Proximal Connectedness (Davies, 2002, p.65). In order to achieve this, the assessor would need to have knowledge of the principles of storytelling with children, and have the ability to interpret children's narrative in a way appropriate to their stage of development.

Children do not necessarily view different aspects of their lives as being connected, and this may affect their sense of equilibrium. In conducting the assessment, it is important not to attempt to 'rectify' the 'contradictions', but to enter into them in the liminal space in order to understand the child's perspective. A liminal space is a place where children are allowed to express who they are. As adults, we enter their world to observe their points of connectedness and disconnectedness. Therefore, accepting the multiplicity of a child's responses requires the assessor not to dwell on the perceived contradictions but to observe their presence and how they affect a child's perspective, perhaps causing the child to experience disconnectedness from their surroundings.

In Case 6, for example, I picked up on the child's response as contradicting what she had said previously. It would have been better if I could have anticipated and been prepared for this contradiction, as I felt that I sounded confrontational in my approach. My annotations pick this up when I comment: "Making a commentary on the child's answer – is it necessary?" (14/10/08).

The interview went as follows:

R: Ok, here's one; this is like going outdoors and enjoying the countryside.

P: (middle position)

R: Ok and why did you put it there?

P: Because sometimes it can be fun and sometimes it can't cos you're just sitting in the car all bored and everything.

R: Ah you're right, like a car trip you're thinking of but other times, out the car it's a bit more fun?

P: Yeah.

R: What kind of fun places do you go to once you get out the car?

P: I go to the swing park, I go climbing up the mountains with my dad and we swing on a rope that we always make...

R: Going out in the car.

P: (places it on *little bit happy*)

R: I thought you said that –

P: But like when we're going to my dad it can be really exciting and when we're going to my gran's. But when we go on a really long trip it can be really boring.

R: That's true. It depends what is at the end of the journey what you are looking forward to.

P: uhuh

(Case 6; 4:20; 5:30)

While the child's explanation gave new information, my own interjection could have been framed differently so that the child felt I was trying to understand her rather than correct her. An assessor needs to enter into the liminal space so that the game, as interpreted by the child, enables the child to feel that the assessor is part of the process. My response was disempowering for the child.

While the assessor should remain aware of judgements made by the children, he or she can still engage with the child in the liminal space in a way that enables the child to explain their decisions. The game and storyboard allow for the assessor to play the role of the listener who responds and this, in turn, allows the child to elaborate with further information. In the liminal space of a game, there is the element of surprise and drama, and this empowers the child in storytelling and play (Engel, 1995, p.1; Haiat et al., 2003, p.212). An assessor needs to know how to enter this liminal space to play and to observe his own interaction with, and assessment of, the child. This became evident in the interview with Child 6 when she placed the card representing her sister in the middle of the Likert scale. The slight surprise I showed at this was evidence of me being in the liminal space, and encouraged discussion about the ambiguous relationship she had with her:

R: (sister's name) Ok, where would you want (sister's name) to go on this one?...Oh you're not to sure right, why is that?

P: Sometimes she can be really moody and sometimes she can be fun as well.

(Case 6; 2:20)

When working in a liminal space it is useful to know what, and when, information about your life and experiences can be used to facilitate the flow of data and ensure a child's feeling of security. If the assessor does not enter into a liminal space, children may feel isolated and limited in what they are able to share. The assessor needs to possess the skill of how to use "self" as a means to inhabit that space; their own personhood is a resource in offering care and assessment. An instance of this use of "self" took place during the Likert Scaling Exercise, when Child 17 put the card representing his brothers on the "little bit happy" face<sup>278</sup>, when the rest of the family were already placed at the top. I talked about what brothers could be like since I had brothers myself. I was trying to help the child feel less self-conscious at making a slight distinction between his brothers and the rest of the family (Case 17; 27:00).

The dual role of inhabiting a liminal space whilst simultaneously listening and assessing can generate challenges. For example, I did not appreciate the literal association that Child 17 made when talking about his family, which affected my response to the child's comments. The result was that I responded in a way which inhibited the child's input and limited the potential of the encounter to reveal elements of the child's life:

R: Ok, I've got a picture of people here, and they can all represent different people in your home. You don't have to choose them all and I can explain who they are or you can explain who they are...

*Staff interruption by physio*<sup>279</sup>

R: So that can be like grandparents. Do you have grandparents?

C: Uhuh, but they don't live in my house, but.

R: No they don't have to live in your house anymore

C: Oh.

R: I know we have talked about the home. This is now talking about these cards.

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<sup>278</sup> Face second from right on the Likert Scaling Exercise, see picture in Appendix 8

<sup>279</sup> The environment of a liminal space can be vulnerable and fragile in a paediatric healthcare setting and interruptions can be an added challenge to maintaining the flow of concentration. This may have contributed to the lapse in explanation that caused the following confusion.

C: Right.

(Child 17: 3:20)

During the transcription of this interview I notice this error and noted in my annotations (referring to the highlighted passages above):

I make the mistake here and I didn't realize it at the time until I transcribed. The child was completely correct but I corrected the child. I had not explained myself correctly. This is the challenge in that the child is listening and I am trying to listen and conduct the assessment at the same time. 21/9/09

Being in the liminal space requires the assessor to have the skill to empower children to enter into how they choose to use the sorting card game and storytelling board. There is a difficult balance to be maintained between engaging the child's play, whilst continuing to assess the child within this context. If children detect disengagement on the part of the assessor, they could become withdrawn and no longer provide answers, or begin to guess at what the assessor might think is the correct answer rather than reflecting on their own position. To avoid this danger, another set of skills is required to address the reflexivity of the assessor during the assessment.

### *3. Reflexivity*

The compassionate provision of pastoral or spiritual care does not begin with an assessment of another's needs. On the contrary, it begins with an awareness of who we are as carers and what we bring to the encounter (Kelly, 2012, p.1).

Reflexivity refers to the awareness of a person who, in performing a particular role, is conscious of the impact of who they are, what they think and how another might respond to them by what they do. Raising an individual's awareness of these factors, and how they relate to their interactions with others, can be achieved through a number of formal or informal approaches. The desired outcome is to increase an individual's level of consciousness so that they can engage in reflexivity in order to clearly identify aspects of themselves that they should take into account when reaching their findings; or to engage in critical self reflection

in order to improve and become a more competent practitioner. Reflexivity is a term used in fields such as education,<sup>280</sup> research and healthcare chaplaincy. In relation to this research, the opportunity to listen, record and type the conversation between myself and the children, gave insight into my interview style and my abilities to engage with the child. In relation to children, the specific emphasis of reflexivity to be focused on is encapsulated by the social researcher, Christensen, who describes what type of reflexivity is required when:

children often greet researchers, who enter their lives as a stranger, with a frank question ‘Who are you?’. By making this enquiry children encapsulate one of the key processes of research: the working through of the wider notions of who we are to each other? (2004, p.166).

Reflexive skills are essential for the assessment of the child and relate not only to practices (as referred to above) associated with the design of the SAT; but also relate to the child’s perception of the assessor who can be viewed as the “ritual elder” (Moore) or as the “coach”, “teacher” or “the significant other” (Vygotski). The ritual elder, according to Moore (1984) establishes the sacred space (1997, p.83), and in this case the assessor is responsible for establishing the ZPC.

The first step to having a reflexive understanding of another person’s sense of connectedness is for the assessor to understand how his own life is constructed in relation to the interpretative framework of connectedness. The role of the assessor is crucial in the ZPC where he is “the significant other” in terms of connectedness. This may not be presented to the child in such terms, but the assessor’s reflexive skill enables identification with, and relation to, the child on those points of connectedness. Similarly, when making an assessment, the assessor considers findings in relation to this interpretative framework in order to avoid another subconscious framework being used which may affect the understanding of the findings of assessment.

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<sup>280</sup>For instance in further education I self-assessed my learning technique using, “The revised two-factor Study Process Questionnaire” (Biggs et al., 2001), I discovered that I reflected more of the qualities of a deep learner than a surface learner but had both qualities in differing measure. This enable me to understand my learning technique in comparison to others learning technique. Brown *et al* provided an interesting perspective of skilled reflective practitioners who could develop this skill from being a novice to an expert ( Brown *et al*, 1999, p.209). The defining attribute of this skill was to move from “reflection-on-practice” to “reflection-in-practice”. This term enabled me to identify my intuitive actions in tutorials so that I could draw from previous reflected experience and respond within a current tutorial with a course of action that would optimise the learning encounter.

There must be consistency between the assessor's interpretative framework of connectedness and their self-awareness of that framework. The assessor must understand how a child relates to an adult and how, as an adult, the assessor relates to the child (Bruck, Ceci and Hembrooke, 1998, p.140; Ellis and Campbell, 2004, p.1158 Handzo and Koenig, 2004, p.1242). Alldred and Burman, in a chapter entitled "Analysing Children's accounts, using discourse analysis"<sup>281</sup> note that;

Children's 'voices' cannot be heard outside of, or free from, cultural understandings of childhood and the cultural meanings assigned to their communication (Alldred et al. in Greene et al. (eds.), pp.177-178, 2005).

Alldred and Burman, proponents of the use of discourse analysis<sup>282</sup> state that the assessor's subjectivity may affect the clarity of insight through his representation and interpretation (Alldred et al. in Greene et al. (eds.), p.176, 2005). They argue that "the interview is an inter-subjective process in a very particular social context" (Alldred et al. in Greene et al. (eds.), p.176, 2005). An adult must be aware of how a child relates to an adult, and vice versa, as well as how both are affected by the specific context (in this case, the acute paediatric healthcare setting). A significant other is conscious of the influence of the surroundings, just as a ritual elder has experience in preserving the role of the sacred space. He or she must be aware that a space is made sacred by the way that it is used, and that it is influenced and shaped by how the healthcare professional experiences the surroundings from the child's perspective. The naming of the sacred space can be a significant protective boundary in the encounter between the assessor and the child.

The complexity of this was evident during Duncan's interview. We were discussing his schooling during his hospital stay when his mother entered the room. I was conscious that her presence had the potential to change the context we had created between us and I did not wish his answers to be influenced by this. I expressed that concern as part of the interview, in the hope that he might still feel empowered to share his own personal opinion. The only indication I have that this was achieved was that the mother considered that the information

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<sup>281</sup> This is contained in *Researching Children's Experiences*

<sup>282</sup> Discourse analysis online <http://extra.shu.ac.uk/daol/about/>

shared by her son offered her new insight into his life. This would suggest that he was still prepared to share from his perspective and not be influenced by the presence of his mother.

My dual role as healthcare professional and as an adult relating to a child was evident in the way I pursued further meaning from his answers. I sensed that he was not confident or possibly felt intimidated. I reassured him that it was perfectly acceptable to not respond if he didn't know or felt he could not answer. Such intervention must be employed in a considered way. Critics of Vygotski's theory claim that there is a risk of too much intervention which has the potential to inhibit the child's learning. The assessor's involvement should not elicit or even impart information that unduly influences a child's responses.

The assessor's capacity for self-awareness within the healthcare context addresses any inherent theoretical difficulty and also any concerns over the style of the assessment. The assessor must avoid introducing his or her own subconscious interpretation of the child to shape the SAT encounter in any particular way. Gergen and Gergen, in defence of their qualitative methodology, explain the importance of this point:

demonstrating to their audiences their historical and geographic situatedness, their personal investments in the research, various biases they bring to their work, their surprises and undoings in the process of the research endeavour, the ways in which their choices of literary tropes lend rhetorical force to the research report, and/or the ways in which they have avoided or suppressed certain points of view (Gergen and Gergen 2000, p.1027).

The assessor, as the significant other, must realize that the child's perspective of a context may differ from his own and he should be able to compare the two viewpoints. This point emerged clearly in the storyboard section of Case 17 in Chapter 8, when I asked the question about how he would come into hospital. I noticed later in my analysis of the film that Duncan had placed his finger on the "car" card. He had not said anything whilst doing this and not noticing this non-verbal communication, I offered the hospital building as a starting point. The situation was retrieved as he introduced the car later in the story. However, it did reflect my limited perspective in relation to where I considered his story should begin. In retrospect, I think I was too healthcare-centric and did not fully appreciate the child's perspective in the

story-telling. The assessor must take into account more than his own perspective of the healthcare context in order to comprehend fully the child's experience of the healthcare context. The child, from his perspective has, in Bronfenbrenner's bio-ecological model, had a major disruption; the healthcare context, which is usually set in a child's exosystem or mesosystem, has now become part of his microsystem. This has also involved a change in a child's biological context as he realises he needs medication. He is travelling from one context to another and the contextual structure of his life is taking on a new shape.

Duncan's choice of where he wished to start the story indicated where his contextual centre was in the constructing of meaning. If the assessor does not appreciate this shift, then they underestimate the impact of the child's experience of his healthcare journey. Duncan takes this further as he introduces the cleaner at the very start of the story. This again indicates that his contextual centre for constructing meaning is the fact that his sick body is very important to him.

During the interviews I became very conscious of a difference between a pastoral encounter and an assessment. In the former, any information shared by the patient can be viewed as empowering, but in the latter, such information can help to create an accurate assessment and enhance the skill base of the significant other. I felt that I lacked clinical knowledge which might have increased my awareness of the impact of the context on the children. I realised that in my pastoral encounters as a chaplain, I used my lack of knowledge as an empowering technique in the encounter, as it allowed the patient to explain something to me that I didn't already know; but I had not considered how much time this took in my routine visits. For example, when Duncan started to take control of the story, he stated that the reason he was coming into the hospital was because his "port-a-cath needs flushed" (Case 17; 29:00).

During the interviews, I tended to request information that may not have been pertinent to the story or spiritual assessment, for example, when I asked Duncan why his port-a-cath needed flushed his answer was simply "to make me better." (Case 17; 29:00). It became evident later that, as a chaplain, I was not aware of the detailed procedures he required and not having that information made me feel anxious to have the complete facts before exploring further. The gathering of this extra information affected the momentum of the questioning in the assessment. This happened when I asked Duncan about his diet:

R: Right, ok, I'll go through these and explain them. You can just take your time.

These two here are to do with eating. Some bits are healthy and some bits are unhealthy. What ... are they important to you when you are in hospital?

C: Uhuh.

R: They are right, ok. Well what you can do is that you can place some of these on and if one card comes up and you think "oh, that one's more important than that one, I'll swap it round." You can do that.

C: Ok.

R: You can put it on but then you can swap, ok, is that all right?

C: Yep.

(Case, 17; 1:10)

In the highlighted section of extract above I made a comment in my annotation:

"I sense in my tone of voice that I'm slightly disappointed. I can detect it myself but I'm not sure if that was conveyed as I soon follow through with the right procedure. I keep forgetting that diet can sometimes play a significant part in a child's maintaining of their condition. This card eventually became one of the significant cards. The physical dimension to a sick child's life can be the source and foundation of developing meaning. It could be a spirituality of survival. A child returns to core issues that make all other meaning possible. (21/9/09)"

This annotation indicates that I did not fully appreciate this aspect of the child's life. As a result, I focussed on the process and in so doing lost the content and moment of Duncan's sharing. I underestimated what he felt when he later said that "Healthy eating makes me happy because I get strong". Despite my underestimation of these simple but deep statements, the design of the tool meant that the card was not marginalised as I maintained the procedure.

It is important, too, not to transfer the dimensions of my own life into how I evaluate the dimensions of the child's life. The assessor needs to keep in mind the interpretative framework of connectedness to define both the assessor's connectedness and the child's connectedness. This comes across in the following extract when the child pointed to a card from the selection of "people" cards:

C: That's like my nephew, I have a nephew.

R: You have a nephew, but the important thing I want to ask you is are these people important to you while you are in hospital?

C: Uhuh.

R: They are? Who's important to you when you are in hospital?

C: Ma nephews and ma brothers and ma sisters.

(Case 17; 4:30)

In the annotations on this section, I comment that “I had underestimated the place of these nephews and the emerging importance of the family. Is that because I come from a scattered family and we do not live in the same locality like this family who have all stayed close? 21/9/09”. This boy was from a large family who had all stayed close to each other and he was the youngest of seven. This contrasts with my own experience of family who scattered throughout the United Kingdom, and where nieces and nephews were never part of my daily routine. The assessor, in adopting the role of a significant other, needs to be aware of his own social profile and the implications this may have on appreciating the child's social profile.

When the lifestyle patterns of the children differ greatly from those of the researcher, a mental conflict may be created. The following incident gave me concern as to what I would consider acceptable from my own perspective as a parent.<sup>283</sup> While I conveyed nothing verbally, I had to internally evaluate my capacity to continue with the interview without making judgment. When interviewing Child 12, during the Likert Scaling Exercise discussing holidays, I felt uncomfortable about what I was hearing. It made me hesitant to explore further, uncertain of what might be revealed:

R: Go away on holiday somewhere. What are you thinking about when you put it away up there?

P: The beach ... Got all the fancy hotels ...that you go in ... and all the big swimming pools and all that ... Me ma brother and his pal went tae, where is it (name of destination) ... for two weeks ... Ma maw was pure greetin because she didnae wan anything to happen to me.

R: Were you away yourself?

P: No I was with ma brother.

R: You were with your brother, how old is he?

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<sup>283</sup> In terms of legislation it was acceptable

P: 18, and him and all his pals

R: And he took you? ...

R: Was it good?

P: Brilliant, man ... uhuh, it was always a laugh (words unclear) always bringing girls back to the hoose, annoying.

(Case 12; 10:40)

While this gives an insight into this boy's family and the responsibilities they are prepared to share, it also reveals how different values can affect the assessor's listening skills and the direction of the conversation. I was listening to this story being aware of my role as a parent, who would not have made a similar decision as the parent of Child 12 did.

The reflexive skills of the assessor are not just about having self-awareness, but having that self-awareness described in terms of the interpretative framework of connectedness. This framework has been used to define my own life in order that I avoid in any way inadvertently transferring assumed conceptual structures of spirituality onto the children I interview; and risking misrepresenting and misinterpreting the connectedness of the child in the process.

The Zone of Proximal Connectedness (ZPC), in terms of reflexive skills, harnesses the role of the significant other to provide a space where the child feels able to share information. The assessor must have the capacity to understand the clinical context, the child's context and his own context. This allows for a better sense of connectedness, where the assessor is able to identify the crucial points of connectedness for a child who is sick in hospital.

#### *4. Connectedness (Fluency)*

The skills of connectedness exist at two main levels; firstly, the assessor should be able to identify those key points of information which describe a child's momentum of connectedness; and secondly, the assessor should earn the trust and respect of children so that they will feel able to share information which reveals their ultimate concerns. This can be described as a point of connectedness between the child and the assessor. Myers notes that:

they ceremonially preserve certain patterns as they provide occasions in which the dynamics of transcendence can occur (Myers, 1997, p.78).

The fourth element in the Zone of Proximal Connectedness provides the basis for another skill-set; what Myers refers to as the “expectation of transcendence” (Myers, 1997, p.79), and what Vygotski’s theory defines as the move from the “known to the unknown”. In Ritual Process Theory, this is identified as “a presence of the ultimate that is beyond the immediacy of the moment within such sacred space” (Myers, 1997, p.82). This combination of theory relates closely to the interpretative framework of connectedness in terms of the momentum of connectedness and the awareness of connectedness. The reason for the momentum for connectedness is that there are times during the assessment when children might acknowledge or connect with what is happening and relate to their ultimate concern. This is observed when there is a disclosure of information that is of ultimate concern or even intermediary concern. In relation to the child’s intermediary concern, Bronfenbrenner’s idea of a joint molar activity illustrates that the assessor and the SAT serve as an identifiable dyadic link to a system which hosts aspects of a child’s ultimate concern.

The assessor’s skill-set in the assessment, in terms of connectedness skills, is to discern a moment of disclosure or investment of information where a child understands and is committed to a healthcare journey which the assessor believes contributes to the child’s connectedness. This connectedness is to the current process of the SAT, to the assessor and to the content of discussion. The assessor should be able to identify these in order to convey this to the rest of the team. Similarly, if there is a disconnection, the assessor should ascertain whether this is with himself, the SAT, the material or the context the child is in. This will enable the healthcare team to be aware of how this child is disconnecting from the surroundings and what measures should be considered if a child remains in this state. The assessor needs to identify when a SAT unsettles the patient as this may indicate a need, although it may not be articulated sufficiently to suggest what the next step might be (Gilchrist, 2001, p.27; Walton, 2002, p.5).

Swinton offers the description of such a skill in relation to a profession. He states:

Most of what chaplains do relates to the listening to and the telling of stories. Stories reveal a form of knowledge that is not only grasped with the mind but also with the heart. Stories demand interpretation,

intuition, imagination, all gifts which are fundamental to chaplaincy when people are practicing well (Swinton, 2003, pp.6-7).

He continues:

Such a practice of intuitive, narrative based chaplaincy when it is embodied and worked out may offer a beginning point for the establishment of an identity of chaplaincy that retains its integrity without losing its relevance (Swinton, 2003, p.7).

Swinton's concern is to identify the essence of what healthcare chaplaincy can specifically contribute to the care of the patient. The concern in this chapter is to articulate the skills required to achieve the connectedness that allows that to take place. Swinton provides the dimensions of a skill-set that is both cognitive and emotional. Whether it contains only these two dimensions is debatable, as four dimensions were required in order for the SAT under study to encompass the interpretative framework of connectedness in children.

Connectedness needs to be accessible at several levels for the flow of information to be forthcoming. The skill-set which takes into consideration a child's ultimate concern must access the dimensions of connectedness a child wishes to use to disclose information.

While much of the information from the interviews conducted for this thesis reflects ultimate concerns about relationships and the child's quality of health, there were other aspects such as having "fun" which were a focal element of a child's sense of connectedness.

Some of these points of connection were through humour and acknowledging that "fun" served as a connection between assessor and child. This was a factor in Case 13:

P: Just rolling about and stop ten minutes later and he says sorry and then we play again and then fight again and then argue a bit, so (child laughs).

R: It sounds like fun, is it fun at the time?

P: (child laughs)

R: Here is a picture of a grown-up guy and a grown-up lady. Who would they be for you?

P: Ma uncle (name) and ma auntie (name).

R: What about your mum or your dad?

P: Oh that ma mum, that could be. She makes me really really happy.

R: Uhum, why did you choose your aunt and uncle before your mum and dad?

P: Cos they are funnier .. ... they let me get away with stuff that ma mum and dad would never let me do

R: Is that right?

P: And they've got a parrot.

(Case 13; 10:30)

The points of these “connectedness” moments with a child were quite varied. Case 5<sup>284</sup> shared a key aspect about his life through the strange nature of his treatment in relation to his eating patterns:

R: Can you eat nice healthy food in hospital?

P: Yes ... but I'm allowed to eat as much unhealthy food as I want.

R: You can, who told you that?

P: The nurse and the doctor...

Dad: The doctor ... the potassium is low ... the doctor told him to eat as much chocolate, bananas and crisps as he could.

R: How do you feel eating all those foods and being allowed to do it?

P: I feel like a king.

R: You feel like a king, do you? Wow, and what do kings feel like?

P: Proud.

R: Do they feel proud? Proud of what? Well what would you be proud of?

P: Being the king.

R: But are you proud of being anything

P: Yeah being with my family ... just one good thing about going in hospital – you don't have to get your dinner. Your mum and dad have to do it. You get to be the king.

R: Is that you being the king again is it? ...

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<sup>284</sup> This child was a cardiac patient who still had to deal with chest drains and was confined to bed.

P: One more thing, you don't need to do work. Your mum and dad has to get it because you've got all these injuries because you can't move because you've got sore legs and sore arms, you've got a sore body you've got a sore ankle.

R: So is it good that they are here to help you?

P: Yeah, and let them do what you say because they are like your servants.

R: Is that right and em do you think that is nice that they can do that for you?

P: Yes, it must be tiring for them.

R: Is that right? Do you think they will be strong enough to do that for you?

P: My dad and my mum, not my mum but my dad.

Child 5 (34:30)

Child 5 felt able to share and make a point of connectedness through several factors working simultaneously; the sense of safety he felt because of the presence of a parent and the fact that the interview took place after a consultation which meant that there would be no interruptions. I sought to provide a hospitable environment which was conducive to the flow of information. I did not question his description of himself as a king, but entered into that liminal space and allowed that to be a means to convey information. While in that space, I was still able to reflect back to him the implications of his statement and this revealed that he was acutely aware of his condition (he had shared elsewhere in the interview about appreciating being alive). This interaction revealed that during this time, when he was not in control of his own body, he was able to use an analogy that enables him to feel like a “king”. This analogy is not without sensitivity on the part of the child who is still conscious of the impact he has had on his parents. I felt that the boy was able to share at a level where he was comfortable in giving information and where he enjoyed the game and story board, both of which achieved a sense of connectedness.

#### **D. Conclusion**

The proposed fourfold skill-set for conducting the SAT consists of hospitality, liminality, reflexivity and connectedness (fluency). This skill-set demonstrates the complexity of specific competences required to engage with children during assessment. The effective practice of these skills by the assessor allows for the successful gathering of information; which assists the healthcare professional to properly interpret children’s sense of connectedness or disconnectedness as a result of their healthcare journey. The initial competences listed apply the combination of Myer’s use of Ritual Process Theory with

Vygotski's ZPD. The assessor's competences complete the component parts involved in creating what I have termed the Zone of Proximal Connectedness (ZPC); the hospitality, liminal, reflexive and connectedness skill-sets are essential prerequisites for the ZPC to occur. The ideal situation is to have an assessor who possesses not just a professional skill-base, but also a specialist set of skills. These skills enable the assessor to make an assessment that provides accessible and transferable information for the rest of the healthcare team.

This chapter represents the last of the three steps that emerged from the convergence at the start of Chapter 6, which addressed the efficacy of the design, discovered the conceptual cohesion of a new term and created an environment conducive for assessment. The conceptual cohesion of the new term and creation of an environment conducive to assessment also completes the two-fold measure required to manage the assessing of paediatric patients through the interpretative framework of connectedness. The assessor, aided by specialist skills, can enable children to share information that captures the special dimensions of children's spirituality. This was achieved through a tool which is designed to encourage children to share information through play and storytelling.

The research process of, and the findings from, this thesis have wide implications. The lack of provision of spiritual care for, and informed by, paediatric patients has resulted in a search for a new conceptual understanding, describing an interpretative framework which takes account of child development and a child's specific context. The outcome offers an appropriate framework to understand sick children; and suggests engagement with them in an encounter to enable children to share on their own terms, at a time when, and in a situation where, they are very vulnerable.

The insights gained through the search to find a construction of meaning that describes a child's spirituality while in hospital; the design and development of an assessment tool to assist the child to share information; the identification of the qualities of the encounter named as the ZPC; and the identification of an assessor's skills to nurture this encounter have significance that might extend beyond the paediatric healthcare context. In order to explore this further a process of theological reflection will establish what other possibilities are available to apply these insights in other settings.

## **Chapter 9: The theological significance of this thesis with regard to the place of children, the role of the assessor and the impact of the encounter: Conclusions and Reflections**

### **A. Introduction**

The health benefits of connectedness are very good. A rich pattern of social connectedness radically improves survival ... We have to give control back to people – to find people’s assets. (Sir Harry Burns Chief Medical Officer for Scotland (14<sup>th</sup> March 2012)<sup>285</sup>

The aims and objectives of this thesis have been met. Through developing a concept of connectedness I have developed a SAT, appropriate for use with children, which uses play and storytelling to enable child and assessor to effectively engage with each other. The thesis defined the skills required for an assessor to make successful use of the SAT; that they must have an understanding of child development theory and the skills to engage with children in a ZPC. Insights gained from the encounter between the assessor and the paediatric patient must be interpreted with reference to the concept of “connectedness”. This concept forms the basis of a conceptual interpretative framework that takes into consideration the stages of children’s development and the impact of their healthcare journey. Although a significant step in addressing the spiritual needs of children in hospital, the development and use of the SAT has wider implications. This research has challenged, and refined, current understanding of childhood spirituality based on the dominant model presented by Hay and Nye (Hay et al., 2006), p.108). Rather than defining children’s spirituality by identifying children’s inherent qualities, this thesis proposes a model that locates meaning between ‘self’ and other; meanings that reflect the developmental nuances of a child in a given context.

This chapter will develop a theological model based in the concept of connectedness; ‘a theology of connectedness’ to assist understanding of the themes which emerge from the new model of childhood spirituality. I am a Christian theologian and this thesis provides a platform from which to apply the concept of connectedness to understanding other aspects of my faith such as God, Jesus and the Church. This will in turn provide me with a basis from

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<sup>285</sup> International Conference, entitled Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing, Harry Burns, the Chief Medical Officer (in his address entitled, “Community Cohesion and Shared Meaning-making: The Heart of Wellbeing”)

which to develop a reflective practice of connectedness that is transformative and calls for a greater mutuality; potentially changing my perspective and practice and making a difference to the person/patient I interact with based on the mutuality of the encounter. The themes of God, Jesus and the Church will be explored through the lens of language, identity, encounter and context, using the work of Bakhtin and Carter Heyward. Exploring these themes has assisted me in my theological work, raising further questions of a theological nature.

### **B. The selection of a theological model**

At the initial stages of theological enquiry as part of my position papers, I turned to Stanley Hauerwas' work, "Naming the Silences" (1990), conscious that until this research was conducted for healthcare chaplaincy, sick children's voices had not been described in terms of spirituality. Hauerwas addresses how theodicy is shaped by the medical culture. However, the success of my methodology in gathering data resulted in a 'chorus of noise', with the mass of data requiring a theological model which would contrast with that of Hauerwas; his having been designed to overcome problems with a lack of data. As a result, a more suitable description of the reflective process would be "naming the voices", which allows for a broader perspective that applies to people other than children.

This new model of reflection can be applied broadly in chaplaincy work; not just when working with children. There are a number of reasons for this. Firstly, the data emerges from dialogue which takes place in a specific context; children sharing their thoughts at a critical and vulnerable time in their lives. For some, it is a transient period where they encounter experiences and people in a context of necessity rather than choice. The conversations provide insight into a perspective of life that would otherwise remain private and confidential. The connections made as a result of these conversations enabled me to develop my thinking, and as a Christian theologian, to explore the wider themes of God, Jesus and the Church. Using connectedness (see Chapter 7) as the identifiable link to understand children, the next step is to view this model as a means to understand humanity on the basis of a theology of connectedness. In order to do this, I have adopted a term used by the school of Bakhtin who refer to a polyphonic<sup>286</sup> model of reflection (Pearce, 1994, p.43). Following Bakhtin's polyphonic model, this final chapter takes the form of a dialogical exploration of the dialogical relationship between my 'personal' and 'professional' self; how these

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<sup>286</sup> This is a specialized use of this word that usually refers to sound but has been adopted by Bakhtin, as a literary term to refer to the different perspectives of characters who contribute to a story.

conceptions of self affect each other; how that relates to my own transformation; and how the insight from reflection on that dialogical relationship can inform and enhance my practice as a healthcare chaplain. If, by engaging in this exercise of reflexivity, I locate a bridging point between the personal and professional aspects of my life and allow each to inform the other it may illustrate how a theology of connectedness can be transformative. I will apply my theory of connectedness to my 'selves' in order to better understand how it can be effective in transforming others (Speck, 2004, p.21).

One skill identified as important for SAT assessors (described in Chapter 8) refers to the importance of attaining the competency of "fluency" through rehearsing of the use of the language and framework to interpret others using connectedness. This competency can serve as a reflexive tool to observe how my own life can be described in terms of connectedness. Fluency is achieved by reaching a point where I have assimilated the framework and associated terminology, so that I can use it to describe myself and the others I care for. Theological engagement with the elements of this reflexive tool can form a basis for my own healthcare chaplaincy practice (and that of my peers) Therefore, what follows is more than a confessional statement or a professional manifesto; it is a search for the integrity of my own sense of connectedness in delivering care to sick children. It is what Heyward calls a dialectical dynamic interplay between the social and the personal (Heyward, 1999, p.36).

"Christianity is both and is always both a revolutionary political and a spiritual home" (Heyward, 1999, p.36). For Heyward, Christianity is the narrative by which she transports and connects her philosophy of life with the world she lives and works in. Heyward's formulation of Christianity as being political and spiritual demonstrates that the social feature of connectedness breaks down the compartmentalisation of different aspects of our lives; challenging individualism and the privatisation of spirituality, and aiming for a social responsibility for social justice. Identifying this in a reflective model of connectedness allows me, as a theologian, to analyse the robust functionality of my faith narrative. The personal outcome of producing this thesis is twofold; a better understanding of how children in their early years construct meaning in the midst of crisis; and an understanding of how my own childhood health crisis contributed to my construction of meaning.

The focus of the application of this reflective model is the Zone of Proximal Connectedness (ZPC); a deliberately created and protected environment which enables meaning to emerge

out of an encounter. The creation of this environment can lead to a clearer understanding of the process of personal development. The raw data gathered in this thesis takes the form of a series of dialogues. The dialogues have been constructed by the children; they have been listened to, read, selected, interpreted and documented by me as the researcher and they have been read by you. The words used to do this form, and represent connections. Valentin Voloshinov,<sup>287</sup> a Russian linguist, states that;

A word is a bridge thrown between myself and another. If one end of the bridge belongs to me, then the other depends on my addressee. A word is a territory shared by both addresser and addressee, by the speaker and his interlocutor (Voloshinov, 1929, p.86).

Using an analogy of a bridge carrying two-way traffic conveys the dialogical nature of that connection, as the function of a bridge is to join two different points separated by an expanse, allowing travel from either direction, and resulting in a two way flow. The territory of the encounter is the bridging point between two individuals and the choice of words are the source of the construction of meaning. The focus on the content of the dialogue, on what is presented through words, is an acceptance of the limitations of our words. Therefore, the focus of this thesis is on the *identified* connections. I argue that the construction of meaning is hosted, created and nurtured in the ‘in-between point’; be that the company of a parent, engaging in a computer game, an intervention by a healthcare professional or even the use of the SAT in this study. This is a departure from the search to explain what lies within a person to what is presented by the person as the place to invest meaning about that person. This is not a search to find what a child’s spirit might be but rather a search for the connectivity of the child and how that informs other’s perception of them.

This chapter argues that the construction of meaning for a child does not reside in any place other than in an encounter and the associated connections that stem from it.<sup>288</sup> This runs counter to the thinking surrounding religion and spirituality as discussed in Chapter 1. The

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<sup>287</sup> Profile Cited 10/9/12 in <http://www.marxists.org/glossary/people/v/o.htm#voloshinov-valentin>

<sup>288</sup> The Martin Buber’s essay “I-Thou” underlines the roots and focus of this current existential theological enquiry. Where there is some measure of departure from Buber is the identifying of what takes place within the encounter. In terms of Buber’s work Is it possible to have a disconnected connectedness that echoes an Ich-Es relationship?

process of reflexivity during and after my research encounters has changed my personal perspective in regards to this.

### **C. A theology of connectedness**

Bakhtin's model can accommodate the approach outlined above by combining different theories which describe the complexity of the organizational axes of a child's connectedness. These are identified using several forms of theological reflection, and are used to traverse between these different perspectives. Each contributes to the strength of the theological model of connectedness. The features of this model are developed under the titles of:

- the public language of connectedness
- the identity of connectedness
- the encounter of connectedness
- the context of connectedness

#### *1. The public language of connectedness: one definition against many*

The choice of connectedness from amongst many available definitions to describe children's spirituality is deliberate. It adopts different reference points from those used previously for spirituality (see Chapter 1). In Chapter 7, the term connectedness was described as an image of an identifiable link between two distinct objects which, by their connection, act as one; both being affected by the established link. In focusing on connectedness the attention is not on the children's spirituality, but instead on the basis for spirituality as theologians and practitioners might refer to it. Connectedness is not merely a semantic switch for spirituality; it is the "interface" between the assessor and their understanding of the encounter with the paediatric patient. However, connectedness is also substantive. Heyward describes connectedness as being part of our existential experience of our knowing that we are relational beings (Heyward, 1999, p.40; Cole, and Pargament, 1999, p.404).

Applying the concept of connectedness as an interface, which describes what is seen and heard, can provide information to be comprehended by the chaplain and other healthcare professionals. Connectedness offers an image without the mystery of terms such as 'spirituality' (Heelas and Woodhead, 2005, p.2). Connectedness is not a projection of what we might imagine the inherent qualities of a child's spirituality to be, but rather the

acceptance that what is presented by a child is what that child has resolved to share at that given point. The information provided by the child and received by the assessor reflects a mutuality of the other (Heyward, 1999, p.39). The challenge is whether the NHS setting can uphold such mutuality and enable a child to present information that might assist in shaping the child's care. An assessor requires the skills to bring about a ZPC which engenders a place of mutuality for a child.

Part of that mutuality is about the choice of words related to definition of spirituality, and in the application of the SAT in creating a ZPC. The previous focus on exploring what spirituality means in terms of providing care has been misdirected; the introduction of an interpretative framework of connectedness reflects a struggle to understand and describe a phenomenon in a healthcare context where spirituality is both owned and disowned by staff and patients. Attention must be given to what is shared between individuals, acknowledging the limits of what can be known by using the concept of "connectedness." Through the concept of connectedness, I aim to offer an interface through which to interpret the narratives used by people in describing their lives and through which to interpret the elusive mystical nature of spirituality.<sup>289</sup>

Whilst spirituality has become a key term for describing a person's perspective on life, there is little cohesive agreement as to how it has been structured (in terms of religion or psychotherapy) to present meaning. Although the term is used freely in popular culture, it cannot be carried over into disciplines which offer professional care. The concept of spirituality is inadequate to describe the universal phenomenon of human anxiety within a clinical context. The use of the term spirituality in professional settings is potentially harmful, coercive and confusing especially if assumptions are made, beliefs of staff are imposed, or the patient is misunderstood or vulnerable. Spirituality, as a term, is unmanageable given its plethora of meanings. Use of the term, based on current understandings of it, could expose patients to unwittingly incompetent care as professional caring staff transfer from what Lyall refers to as "structures of idolatry,"<sup>290</sup> whether based on religion or secularism and leading to

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<sup>289</sup> When I presented some of this material to the Yorkhill Research Study Day, who audience was predominantly medical there was a varied response. One person suggested that I should not use the title Spiritual assessment tool but rather the Connectedness Assessment Tool, while a consultant did not wish for me to have too loose touch with these unexplainable "spiritual" experiences

<sup>290</sup> The use of the term idolatry is taken by Lyall from a thesis by Farley, E. (1987) 'Interpreting situations: an inquiry into the nature of practical theology.' In L. S. Mudge and J.N. Poling (eds.) *Formation and Reflection: The Promise of Practical Theology*. Philadelphia, PA: Fortress Press. (pp.1-26)

the imposition of one person upon another ( Lyall, 2000, p.56). In order to avoid misinterpretation, a deliberate development of language fit for the purpose of clinical care can be more explicit, transparent and accountable.

Heyward's work on the "dialectical dynamic interplay" (Heyward, 1999, p.31) demonstrates how connectedness offers a professional language of care which engages with the phenomenon called spirituality; engaging with what individuals choose to present as their construction of meaning and how that is disrupted by admission to hospital. As a result of its purpose to preserve life and improve health, the healthcare context accentuates people's exploration of meaning and sense of purpose at a point where their own sense of meaning can be lost, recovered or reinvented; what Hauerwas refers to as the "theodicy project" (1991, p.97). A place of meaning must contain the constructive materials for professionals and patients to engage in a partnership with an appreciation of each other's desire for meaning. To achieve this, the concept of connectedness has been developed.

One of the reasons for the selection of connectedness as a term is that it carries a dialogic element in its application to epistemology, in what Heyward describes as "how we know what we know" (Heyward, 1999, p.31). The concept of connectedness explored through the application of a SAT is the embodiment of an epistemology referred to as dialogism (Pearce, 1994, p.6). The application of dialogism, built on a development from Bakhtin's work,<sup>291</sup> allows for connectedness to have contextual contrast (Pearce, L; 1994, p.6). This meaning is encapsulated in the term "answerability" which examines how different, but related, concepts respond to each other and considers whether one can be understood without the other; for instance, space and time, self and other. If the dialogic principle were to be applied to this thesis then the related, but different, concept to connectedness is 'disconnectedness'. If the concept of spirituality were to be considered in a similar way, a contrasting, but related, concept does not exist. To describe someone as 'unspiritual' implies an unpalatable, ontological statement about a person that is beyond the remit of this thesis,<sup>292</sup> whereas 'disconnectedness' would refer to the impact of the contextual setting of a person's healthcare journey.

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<sup>291</sup> Mikhail Mikhailovich Bakhtin is a Russian philosopher and literary critic who studied the meaning and structure of language. His work was in the 1920s but his wider influence did not occur until the 1960s. (Cited 10/9/12 <http://www.britannica.com/EBchecked/topic/49580/Mikhail-Bakhtin>)

<sup>292</sup> Hay refers to the cultural suppression of spirituality in order to explain the absence of a person's spirituality.

Using the concept of connectedness avoids touching on an ontological concept implied by the use of the concept of spirituality, as spirituality focuses more on the individual rather than on the individual in a particular context. I became aware of this distinction during the process of developing the design of the SAT. Initially, I attempted to identify an individual's spiritual profile, before realising that this was not the purpose of the SAT (see Chapter 5). In the subsequent narrowing of focus of the SAT to the specific context of the hospital, a greater freedom was created to explore the contrast of connectedness and disconnectedness, and to explore how that contrast related to children's perceptions of their situation in hospital relative to that of other contexts they commonly experienced. It enabled a more fluid, flexible and focused approach to many varied factors. In using this concept of connectedness the assessor acknowledges the scope of the parameters of a given context and does not project to what it is beyond his means to verify or address. This language of connectedness provides a mutual involvement and empowers both participants, whether it is acknowledgement of need, or responsibility to meet such need.

Connectedness is an effective concept within a socio-historical context as it addresses the immediacy of a paediatric patient's setting. The Bakhtinian term "simultaneity" is useful here; referring to the resonance that takes place between related dialogical concepts where the different positions are dependent on one other. For example, the presence of a family member with a child during a hospital stay can signify connectedness, whilst the absence of that person might result in disconnectedness experienced due to the lack of the means of connectedness. The two terms are relational but at opposite ends of a spectrum.

Connectedness, then, offers a dialogical epistemology. Talking of connectedness, Pearce states that;

It presents us with a theory of knowledge that admits we can make sense of the world we inhabit providing we allow that such meaning is provisional, dynamic and constitutive of two (reciprocating) terms (Pearce, 1994, p.10).

If the means of connectedness is not maintained, there is the potential for the state of disconnectedness to ensue when there is a separation between children and the aspect that they might wish to remain connected to. Hay et al. (1998) describe "a relational

consciousness” which rests more on intrinsic qualities within the child. The difficulty with this perspective is that if a child does not display such a quality, there is a danger that the child is viewed as being incomplete or, as Hay concludes, having suppressed any sense of spirituality. Chodorow, on the dialogical process,<sup>293</sup> insists that “our separateness from others is the dynamic for our dialogic relation to them” (Chodorow cited in Pearce, 1994, p.91). The disconnectedness may not be in the child, but occurs because a healthcare professional has failed to make a connection. Connectedness avoids a ‘patient-centric’ assessment but offers a ‘patient journey’ assessment. Meaning is constructed on the basis of visible interaction with the patient and not from what is presumed to reside within them; otherwise mutuality would not be present.

If a child is to be understood, the processes involved in connectedness require co-operation, dialogue, affinity and agreement. Two hurdles must be overcome if mutuality is to be attained with sick children in the healthcare context. Firstly, healthcare chaplains must come to terms with the full implications of their transition into the public arena of healthcare and be aware that spirituality, as a language, claims too much, carries too much religious history and contains little in terms of insight as to the care required (Hathaway, Douglas and Grabowski, 2003, pp.150-151). It is a language treated by those who use it as being universal in its application, but does not have the clarity to describe specific phenomena. Generic<sup>294</sup> chaplaincy requires a generic language or, more precisely, a professional language that can describe what needs to be known about a child in hospital, so that appropriate care can be offered. The second potential hurdle to the attainment of mutuality is the complexity of views and opinions of healthcare staff. This is compounded by the mixture of healthcare staff that, to varying degrees, adhere to the value system espoused by the NHS.<sup>295</sup> Those responsible for the care of patients have no collective position on how to reconcile paediatric patient-centred

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<sup>293</sup> Nancy J. Chodorow “is an interdisciplinary scholar that describes herself as a self defined interpretive or even humanistic psychoanalytic sociologist and psychoanalytic feminist” and is Professor of Sociology Emeritus, Clinical Faculty in Psychology Emeritus, Department of Sociology at the University of California at Berkeley <http://www.webster.edu/~woolflm/chodorow.html> and <http://vcresearch.berkeley.edu/nancy-j-chodorow> both cited 31st May 2011

<sup>294</sup> Generic is used as a term in healthcare chaplaincy to refer to the non-religious remit involved in providing support.

<sup>295</sup> An example of this is evident in the NHS Scotland educational Services for Clinical Governance where it states that, “The Scottish Executive Health Department has developed the Equality and Diversity Impact Assessment Toolkit (2004) to support the NHS Boards implement and assess the Equality and Diversity approach outlined in Fair for All – the Wider Challenge. The toolkit has been designed to help NHS managers and practitioners to assess, monitor and update their policies and services to meet the requirements of the Equality and Diversity legislative and policy framework.” (This cited on 2nd July 2012 on [http://www.clinicalgovernance.scot.nhs.uk/gen\\_pages/equality.asp](http://www.clinicalgovernance.scot.nhs.uk/gen_pages/equality.asp) )

care within a secular institution such as the NHS, and no collective position on how to deliver spiritual care in a transparent manner.

The problems caused by the lack of a collective position on the delivery of spiritual care can be overcome by providing an interpretative framework of connectedness that provides a linguistic interface to reconcile the functional nature of how a person constructs meaning, and to understand how that relates to a carer's responsibility to deliver care. This constitutes a move away from using a belief system as a prime descriptor of how to manage a person's care (see Chapter 1). Chapter 7 demonstrated that applying the term "connectedness" in a specific context enables those who work in that setting to meet their professional responsibilities more effectively.<sup>296</sup> The development of a concept and a term which are linguistically compatible is appropriate in a context where people meet, share space and have dialogue.

Until now, healthcare chaplaincy in Scotland has unsuccessfully tried to distinguish between religious and spiritual care. Healthcare chaplaincy in Scotland, with its largely Christian origins, has inherited and perpetuated the use of particular language that describes and includes concepts and understandings which lie outside its professional remit. The concept of spirituality is now outmoded. The Scottish government is seeking to address the needs of patients in the NHS, but as yet, it has not considered sufficiently an appropriate conceptual framework and associated terminology. Healthcare staff, outwith the chaplaincy service, can identify the phenomena but there is no common mode of expressing their observations (Bull, 2011, p.17). The interpretative framework, expressed through the term connectedness, offers a new language for assessing the human phenomenon of meaning construction. This framework enables healthcare professionals to have clearer insight into another's reality as well as offering a "dialogic reading" of a child's connectedness (Pearce, 1994, p.16; Nye, 1996, p.112). Such understanding should help NHS staff to deliver appropriate care.

Language is the source of the narrative which has become part of the professional/public domain. The construction of this language of care comprises three parts. They are: the interpretative framework, the design and delivery of the SAT and the adoption of an appropriate terminology. Firstly, the construction of the interpretative framework has been

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<sup>296</sup> This addresses the concerns raised by Moberg (2002, p.57) that address the particular aspects of an individual's life but can be universally applied in the delivery of spiritual care.

informed by the psychology of child development in order to establish a new perspective. Four theories were employed to gain insight into the cognitive, social, faith and bio-ecological development of children in order to mark out the dimensions of connectedness.

Secondly, in shaping the design and delivery of the SAT, Vygotski's Social Cultural Theory was used to establish the founding principles for the creation of the concept of the Zone of Proximal Connectedness. The work of Engel, a child development psychologist who focused on storytelling, was used to develop the design of the SAT to make it suitable for use with children. The study of psychology, in particular of child development, has been a main factor in shaping this study. The range of theories used offers a diversity of views as to how children might be understood, enabling me to create a combined model that complements the different aspects of children.

The third component is the adoption of the term connectedness. In Chapter 7, connectedness was identified as a term that has been used in several fields and it has also been applied in a study of the social networks of patients within a healthcare context (Mitchinson, Kim, Geisser, Rosenberg and Hinshaw 2008).<sup>297</sup> At an International Conference, entitled *Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing*, Harry Burns, the Chief Medical Officer (in his address entitled "Community Cohesion and Shared Meaning-making: The Heart of Wellbeing") made reference to social connectedness as a new way of understanding the health challenges that Scotland faces (March 2012).<sup>298</sup> A significant stage has been reached when the term used in this thesis as a framework within which to assess children's responses to their healthcare experiences, is used in other contexts.<sup>299</sup> Feminist theology has also made use of this term, drawing from the linguistic work of Bakhtin in dialogic theory with particular reference to his work in *Dostoevsky's Poetics* (Pearce, 1994, p.43). The dialogic theory in relation to Bakhtin's work is concerned with identifying the

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<sup>297</sup> The focus of this study is on the benefit of social connectedness. It does not have the same complexity of connectedness in this thesis when it describes social connectedness as "Social connectedness refers to the overall quantity and quality of relationships that individuals experience." (p.292)

<sup>298</sup> Cited on 24/4/12 - <http://www.enhcc.eu/120313SpiritualCareandHealth.pdf> The referencing he made during this presentation was a commentary of how he understood the social problems that contributed to the health challenges he was responsible in addressing.

<sup>299</sup> At the *Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing*, International Conference Harry Burns the Chief Medical Officer in his address entitled, "Community Cohesion and Shared Meaning-making: The Heart of Wellbeing." made reference to social connectedness as a new way of understanding the health challenges that Scotland face. (March 2012)

multiple voices contained within a text and how they connect with each other. This linguistic paradigm illustrates how connectedness can function at a theologically reflective level.<sup>300</sup>

The exploration contained in this thesis has been dominated by the study of psychology and this was an unnerving process<sup>301</sup> of investigation for me, when theology was yet to play an explicit part in unearthing insight into the work of a healthcare chaplain conducting a spiritual assessment with a paediatric patient (Pronk, 2005, p.421). However, the dialectical nature of the exploration yields a vein of theological gold. Graham et al. state that:

The dialectical strand stresses the possibility of theological understanding being glimpsed in ‘secular’ thought forms and argues that these make a vital contribution to a living theological tradition (Graham et al., 2005, p.139).

The use of the dialectical process has raised questions as to whether there is sufficient interaction between proponents from the fields of child development and theology. It is acknowledged that the current situation of spiritual care is inadequate and does not help caring staff to have a unified approach to addressing the needs of children. A more effective approach to childhood spirituality is required, and combining insight from these fields of study allows for them to inform each other to create a new perspective. This research aims to offer a practical means for healthcare staff to utilise a relevant, common language of care which takes into consideration the developmental dimension of a child who is displaced.

The structure of the interpretative framework of connectedness draws from developmental psychology. Bakhtin’s dialogical process offers the insight required to create a new perspective to assist the healthcare professional appreciate how children construct meaning. The purpose of engagement with psychology and theology is to offer a new interpretative framework which gives a depth to a professional language (or at least one that transfers easily

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<sup>300</sup> This can encompass the challenges of qualitative research that acknowledges the multiple realities it can create (Woodgate, 2001, p.153) This is acknowledged by Benson, Roehlkepartain and Rude (2003) who identify the complexity of spirituality and how different areas of enquiry from psychology and social sciences are just some of the voices in the midst of this call for broad research.

<sup>301</sup> The reason for it to be an unnerving process reflects my roots in theological training and having a sense of responsibility to engage in this manner. It also illustrates my awareness of the default mode I adopt in the theological reflective models I have used prior to this thesis that erred more to a didactic rather than dialectical mode.

among the healthcare disciplines) and so there is, “a translation of a text into another language” (Graham et al., 2005, p.31). The interpretative framework of connectedness can become an “internal interlocutor” providing a new reference point from which staff can understand children, and understand themselves in relation to children. It allows an internal conversation to take place so that a healthcare chaplain can conduct an assessment of a child and share his findings. This approach to assessing spirituality in children has been adopted before, but limited use has been made of child development theories. Perspectives from multiple theories are required to understand the complexity of a child’s development and to understand how development and ecology contribute to the child’s construction of meaning. The interpretative framework of connectedness necessarily includes the creation of a reflective practice tool that integrates the methodology and conceptual structure of understanding and delivering care.

The need for such a cohesive framework arises as a reaction to the patients’ experiences of rationalisation or dehumanisation within the healthcare system. Is the concept of spirituality a resurgence of Romanticism where beauty and emotions play a significant part in shaping and interpreting a person’s surroundings? (Graham et al, 2005, p.148). If so, then healthcare professionals need to come to terms with the ways in which people understand and construct meaning. While Heyward (1999, p.47) would go further, saying that such concepts speak of aspects of our lives that are beyond our knowing, it is sufficient that secularists should not need to accept an intellectually unpalatable philosophical framework. Working with the public requires staff to engage with people who believe and construct meaning beyond their own experience. The concept of connectedness allows us to observe that in each other.

Therefore, this dialectical process is not designed to convince others of a religious belief, nor to argue about how God can be comprehended, but rather to recognise the needs of those requiring care and how to connect with them in order to understand how they connect with their lives, which may, or may not, include religion.<sup>302</sup> It is important that this approach is not misconstrued by a person from a secular perspective as being a disguise for “God-Talk” (Graham et al., 2005 p.148), but rather as an opportunity to have a professional language which can be owned and used. The interpretative framework of connectedness is not designed

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<sup>302</sup> In one respect, what is being argued is for a healthcare practitioner to understand how someone does comprehend God and how that corresponds to how that person’s healthcare journey.

to discover that “the deepest fulfilment of our humanity is to be found in the religious quest” (Graham et al., 2005, p.148).

Articulating the concept of connectedness involves naming contextualised feelings that can be understood by those from both secular and religious perspectives so that they can engage sufficiently to understand what the other describes. The religious community can no longer monopolise ownership of this context and secularists must accept that to deliver care means that there must be a language which is inclusive and universal within the phenomenon described as connectedness.

This is described by Graham et al. who note that:

The task of articulating a body of understanding by which people can live meaningfully in today’s world is fundamental to the theological enterprise. This necessarily involves engaging with the dilemmas that preoccupy them and advancing responses that are both theologically authentic but culturally relevant (Graham et al., 2005, p.154).

In respect to the engagement between theology and culture I have followed on from Tillich who explored “the existential importance of psychological terms” (Graham et al., 2005, p.157). I have sought to understand how children construct meaning, not just in terms of stage and social theory, but also within the disruption of their normal context. Unlike Tillich, however, my aim is not to make “Christianity understandable”, but rather to create a conversation in the healthcare setting which helps staff to understand children better; allowing theology and psychology to contribute to these insights what has been termed as “critical correlation”, “revised critical correlation” or a “process of mutual interrogation” (Graham et al., 2005, p.160). Tracy, in his model of revised critical correlation, proposed that he holds the two strands of the correlation model of apologetics and a dialectical process (Tracy cited in Graham et al., 2005, p.160). It appears that in this thesis the first strand has been dispensed with and I am left with the dialectical process. The dialectical reference point is not Christianity, but the phenomenon now described as connectedness.

What does this new language of connectedness describe? What are the points in the construction of meaning? The second question leads into a discussion of the first; the identity of connectedness.

## *2. The identity of connectedness*

Connectedness describes the construction, or at least the discovery, of meaning between two individuals. Indeed, it can also be the creation and construction of meaning; it can be something new. Children's awareness of their connectedness emerges from the dialogue they have within themselves as they address the disconnectedness they have experienced between hospital and home. Similarly, the assessor is in dialogue within himself about the current assessment and those conducted previously. The substance of those internal conversations has the capacity to form part of the process of assessment. The assessor is a professional representing other professionals, while children might have a sense of representing their families. The interpretive framework of connectedness is the mapping of these internal dialogues. We are trying to pinpoint the source of these internal voices through the use of the SAT and the interpretative framework of connectedness. Within a dialogical framework, the healthcare chaplain would be the addresser and the paediatric patient would be the addressee. The addresser instigates communication and engages with the child who reciprocates in relation to what the addresser raises. This is what Pearce refers to as a "dialogic contract" (Pearce, 1994, p.4). A dialogic contract formulated through the use of a SAT can be empowering for both participants, as it makes explicit what is taking place between the two parties. Prior to the use of a SAT, all encounters involved a "dialogical contract" but it is probable that neither party was aware of what had been agreed to.<sup>303</sup> The formal nature of a SAT ensures that all parties are aware of what is involved and have agreed to it. The tool in itself will assist in delivering assessment and care, but the process of the SAT encounter is only complete if the assessor is aware of his position of power during an assessment.

The Bakhtin group refers to the power in a dialogical contract as being evident through "intonation" (Pearce, 1994, p.4). For the addresser to communicate in a different manner, a change in tone of voice is sufficient. This is evident from the intonation used by some

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<sup>303</sup> It is possible that with no dialogical contract the opposite can take place. Thomas Moore (2010) in "Care of the Soul in Medicine" comments, "Healthcare professionals sometimes worry about being too involved with their patients, and so they go out of their way not to connect. . . . But there is a faulty psychology in this common belief in emotional disengagement. Disconnecting is a form of repression." (pp.26-27)

children during interviews; at certain points the intonation of a child changed as he/she disengaged from the interview process and made a side comment for clarification. This indicates the power of engagement adopted by children who are committed to the process, suggesting that they project a particular identity they are prepared to share, and allowing the assessor to support what they wish to share as part of the dialogic contract. Children are projecting an identity during the SAT encounter that they have agreed within themselves and which they feel should be supported and cared for (Aldridge, 2002, p.34). As such, a healthcare professional receives a clear indication of what is needed in terms of care at that time. Children may share other identities in relation to other aspects of their lives with other people at other times. While the nature of all of these identities may not be observed, they function as dyadic links.

The focus on projected identity empowers the individual and makes the information received more valuable as it becomes more transferable and communicable. What I have been unable to answer in this thesis is: “Can the construction of meaning between a healthcare chaplain and a sick child translate beyond the encounter, so that others can use the information from this SAT encounter to inform identifiable links during the rest of a child’s healthcare journey?” This will be possible when there is acceptance by all of the healthcare team that the chosen identity presented by the person is the basis for care. This is the basis for mutuality.

A key factor in whether the ZPC can be achieved is the reflexivity of the assessor. Graham et al. (2005) (in *Theological Reflection: Methods* and in particular in their Chapter “Theology by Heart: The Living Human Document”) refer to the reference points that an individual can use for theological reflection. There have been times in this research process when the use of “self” has played a key part; particularly when the practice of reflexivity was required to ensure that I was more aware of my involvement in the whole process (Graham et al., 2005, p.19)<sup>304</sup>. The use of “self” in relation to how to connect and understand the child during the interview, in addition to the interactive impact we had on each other, must be framed by the identity of connectedness.

A child’s identity is a changeable factor; Bakhtin talks of people in terms of “social subjects” or “subject acquisition”. If a child’s experience is causing disconnectedness, the child may

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<sup>304</sup> I recall one particular position paper where I was asked by my supervisors to write a reflexive paper on my own self awareness as a researcher.

wish to find a way of connectedness.<sup>305</sup> The identifiable link between these two dialogical positions is where meaning is constructed and identified. In this encounter, identity is perceived, shared and communicated. The data presented are not owned solely by the individual; rather they show how that individual interacts with another individual in relation to the connectedness of each at that point.

The identity of connectedness captures the dynamic and interaction that is taking place between the child and the assessor. Bakhtin's architectonic<sup>306</sup> model is valuable here in explaining that an individual's identity does not belong only to them. Identity is a suitable word to explain this specific aspect of connectedness in the context of healthcare. An 'identity card' contains an image and a name and is issued by an organisation to permit a person to function in a particular context. Others who see the identity badge are able to relate appropriately, with the reassurance of the visible permission of the healthcare's professional accreditation and the institution's endorsement. The identity of children, when a SAT is being conducted with them, is an arranged context where there is an agreed projection by the children as to how they wish to participate. The identity they select is beyond who they are, but allows their peers to interpret that identity. The complexity of a child's identity is taken into account in the four dimensions of connectedness developed from different theories of child development (see Chapter 7). Connectedness is not a static concept applied to a sterile setting, necessarily having a developing and appropriate application to a child in a healthcare setting.

Bakhtin refers to an individual whom he viewed as "unfinalisable", suggesting that this incompleteness was a characteristic of the person. If this idea is related to child development, and particularly to Piaget's cognitive theory, connectedness is seen as a biological and contextual experience of recurring connections which reveal the cognitive style of children

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<sup>305</sup> The assessor needs to differentiate between how that sense of disconnectedness relates to them and that of the child's environment. The environment in this context is understood through the dimension of a child's awareness of connectedness.

<sup>306</sup> It is here also that Bakhtin introduces an "architectonic" or schematic model of the human psyche which consists of three components: "I-for-myself", "I-for-the-other", and "other-for-me". The I-for-myself is an unreliable source of identity, and Bakhtin argues that it is the I-for-the-other through which human beings develop a sense of identity because it serves as an amalgamation of the way in which others view me. Conversely, other-for-me describes the way in which others incorporate my perceptions of them into their own identities. Identity, as Bakhtin describes it here, does not belong merely to the individual, rather it is shared by all

and the nature of their resilience of connectedness. Bakhtin asserted that people are constantly influenced by others and that what they express is due to their surroundings.

His view of a person being “unfinalisable” addresses those who have treated Piaget’s work as a means to define a child merely by cognitive capabilities. Bakhtin’s view is that incompleteness can be part of a person’s identity and a continuing attribute. Identifying such a feature in a child who is in a new context, such as a healthcare setting, would add to a way of understanding that child. This is not to disregard Piaget’s work, but rather to identify the predominant features (e.g. biology) which take place in a child’s development and to allow connectedness to be a cohesive link to hold together these developmental theories.

This application of the dialogical principle from Bakhtin’s work indicates the conduit role that the concept of connectedness has in understanding the whole child. The dialogical principle is that the voice of a child is developing in terms of their stage, but also maturing its diversity to relate to different context adding different means to relate. Bakhtin uses the term polyphony to describe the multiple voices interplaying in the development of the child; each contributing to the child’s understanding. The assessor’s aim is to discern these voices and by doing so, to identify the features contributing to a child’s (dis)connectedness. The assessor applies the principle of a polyphonic truth in relation to connectedness and so has the resources to connect with several contexts, theories or systems.<sup>307</sup> The connecting agent in this process is the assessor and therefore it is critical that there is a developed reflexive model of connectedness to explore the assessor’s own identity.

During this research, there was a change in my identity as the assessor. This was evident when it became necessary to change the SAT design and the importance of gaining information about the experience of the healthcare journey within the hospital context. The nature of the information sought from the child was changed, as the wide scope of information gathered in the earlier interviews had generated within me a need to corral the child in order to stay focused. In later interviews, the information sought focused more on the paediatric healthcare context and how the patient related to this context, rather than to an unspecified setting. I have become conscious that there was a conceptual shift in my thinking

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<sup>307</sup>“It is the fact of mutual addressivity, of engagement, and of commitment to the context of a real-life event, that distinguishes truth from untruth.” Mikhail Bakhtin, p.139 *Information Theory*, Pedia Press cited 10/9/12, [http://books.google.co.uk/books?id=3P8poWAeHisC&pg=PA1&source=gbs\\_toc\\_r&cad=3#v=onepage&q&f=false](http://books.google.co.uk/books?id=3P8poWAeHisC&pg=PA1&source=gbs_toc_r&cad=3#v=onepage&q&f=false)

related to this focus in the design, and also a conceptual shift in my understanding of what it means to relate to other individuals and their own connectedness. In relation to the use of reflection of self as the living human document, Graham et al. observed that: “this method enables reflection on the self by examining documents that turn-life-into-text” (Graham et al., 2005, p.20).

My research provided the opportunity for self-exploration through annotations, journaling, recording, coding and cataloguing of the interviews conducted with the children. Principally, these activities were a means to an end; but the shift in thinking they prompted in me, serves to illustrate that a process of identity formation is required on the part of prospective assessors. As a crucial part of the training procedure, assessors must develop an appreciation of their own connectedness in order to engage successfully through the SAT. However, further investigation of methods that an assessor might employ to create an identity of connectedness is needed.

A SAT is a means of constructing meaning at a point of connection. It is an insight into the identity of the child encountered by an assessor. Information gathered must be used carefully, and assumptions must not be drawn from it. This leads to the third aspect of how insights can be gained in the encounter of connectedness.

### *3. The encounter of connectedness*

The theological exploration of the interviews documented in this thesis offers insight into the wider implication of the encounter of connectedness. The encounter of connectedness is the source to construct meaning of ourselves, of the other, or a relationship.

The encounter of connectedness moves in a different direction from Hay and Nye’s influential concept of “relational consciousness”. Connectedness in this thesis is not an ontological construction but a contextual link that formulates an individual’s reality through their “dialogical imagination” (Heyward, 1999, p.48). A person draws meaning from the interaction between two individuals, e.g. the content and manner of conversation between two individuals adds to their understanding of their relationship. It is also possible for a person to establish a sense of meaning from the interaction with an object, e.g. a child

cuddling a soft toy.<sup>308</sup> According to the concept of ‘relational consciousness’, their concept consists of awareness sensing, mystery sensing and value sensing; the dimensions of connectedness are not intrinsic within the person but are anticipated in an encounter. Connectedness is the visible and verbal statement of what is made visible and verbal between two individuals. These visible and verbal statements represent what is experienced and imagined; it is the fantasy of an imagined world that may exist in the mind of the child or be discovered in the ZPC and constructs meaning through what has been communicated and the act of communication itself. Connection is not a projection of qualities into a person’s being, but the projection of his or her identity during an interaction.<sup>309</sup> Hay notes that “Spiritual talk ... was identifiable because it always had to do with relationship, not only relationship to God, but also relationship to other people, to the environment and even to oneself” (Hay, 2003, p.4, 121). This definition lists the content of a child’s focus, but it loses the dynamic of the construction of these connections, how and where and with whom they were made.

The encounter of connectedness contains the interactive dynamic of dialogue that involves variables of context and development. Connectedness spreads from the centre of the encounter and does not emanate solely from the individual. Connectedness does not overstate what children’s spirituality is, but demonstrates how it is presented by the child. Therefore, connectedness is no longer a projection placed upon the child; a theology of connectedness is a commentary on the way the child and the world connect with each other. This resonates with Heyward’s work on mutual relations and has implications for the professional in relation to the responsibility and authority given by an institution and in relation to the empowering, liberating dynamic proposed here. The chaplain must have the ability to empower a child to share and must be able to reach a point of engagement where there is a mutual encounter. Otherwise the SAT could be considered as another guise for institutional authoritarianism (Heyward, 1999, p.58). If a healthcare chaplain draws from a religious narrative, then his theological roots will be embedded in a narrative of God which engenders mutuality for him to use connectedness as a reflective framework. This touches the essence of what is being discovered through an assessment. Heyward directed her readers to appreciate that “by ‘relation,’ I am speaking of the radical connectedness of all reality, in which parts of the whole are mutually interactive” (Heyward, 1999, p.62).

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<sup>308</sup> Could this also relate to Buber’s work?

<sup>309</sup> It would be more accurately the projection of an identity that is affected by the context within which they

It is important to identify what this process of encounter can mean when connectedness is used as a reflexive tool. To demonstrate this, I have selected a period of time during my studies to illustrate how an assessor's fluency competency level might be built up. An auto ethnographic<sup>310</sup> position paper, submitted in August 2009, entitled "It's all about me" provides the basis for the material discussed. This was a personal reflexive exercise written to address a difficult point in the development of the PhD study which coincided with a time of personal loss.<sup>311</sup> The paper became a means of inter-relating the professional, academic and personal dimensions of my life. In order to analyse this material now, I will apply the four dimensions of connectedness, as outlined in Chapter 8.<sup>312</sup>

In terms of my momentum of connectedness,<sup>313</sup> my ultimate concern at that period of time was my family. I experienced a strong disconnectedness due to the loss of my mother and this reinforced my sense of momentum of connectedness with my immediate family. The intermediary concerns which assisted me in focusing on my ultimate concern during that time of disconnectedness were filling my life with activity, one of which was the reflexive paper referred to above.<sup>314</sup> The awareness of connectedness resulted in a disruption of my mesosystem with the loss of my mother and the cessation of visits to her home. This dyadic link was broken, but others were strengthened through my personal network of friends and wider family. The resilience of connectedness involved a gradual return to equilibrium. My cognitive style drew from past experience of loss, but experienced different issues which required dyadic links to assist me in assimilating a new stage in my life. The evaluative nature of connectedness helps me to understand the social behaviour that I sought during that time to construct my sense of meaning.<sup>315</sup> The tension between integrity and despair were very real during bereavement, but this was countered by my daughter's wedding later that year when I fulfilled my responsibilities. This enabled me to have a natural means to channel my evaluative nature of connectedness that affirmed my integrity. This is one thread of

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<sup>310</sup> Auto-ethnography is a form of qualitative research that allows the person to use self as the source of data in the study.

<sup>311</sup> This was written in the months following the death of my mother in later May 2009

<sup>312</sup> For the sake of keeping the illustration concise and simple I extract one strand from this position paper to show what this means when identifying my momentum of connectedness, awareness of connectedness, resilience of connectedness and evaluative nature of connectedness..

<sup>313</sup> The faith development theory is immediately accessible to an adult as Fowler's stages relate to all ages in a person's life.

<sup>314</sup> One of my desires was to share in my joy with my mother in completing my PhD. The focus on the PhD work was a sense of connection to the existing memories of my mother during this early stage of loss

<sup>315</sup> In terms of apply this aspect of connectedness it is possible to apply Erickson's later stages of social and emotional development to relate to my stage of adulthood.

connectedness, but the intermingling of that time in relation to the narrative of this paper reveals further insights of connectedness. In the opening sentence I state that:

At one level, this thesis is a professional search to perform a better job. In other ways, it is an inescapable journey of self-discovery.

The significance of this phrase is echoed throughout the paper. In terms of connectedness, the paper acted as a dyadic link, blending my professional work with my ultimate concern for my family. I rediscovered the significance of my mother's supportive role in my past, when I was a paediatric patient, and in the present through her interest in my PhD studies. Writing the paper acted as a dyadic link with my microsystem, chronosystem and mesosystem. The paper created links to my previous experience; created links to the expression of my personal journey; and served as an opportunity to explore my reflexivity with my supervisors.

This personal example illustrates what is involved in applying connectedness and suggests that its use can enable me to be competent to understand what aspects of my own life might affect how I listen and engage in the assessment of another. The scope of connectedness allows me to structure my story and communicate it to others. This process of engagement can help me to understand and structure another person's story. This is highlighted by Graham et al. when they assert that:

It is important to recover a sense of the disturbing parabolic nature of stories if we are to offer an adequate response to the tragic nature of experience (Graham et al., 2005, p.49).

If the dimensions of connectedness can be used to increase self awareness of my story and in turn, to understand another's story, is it possible to discover a reconstruction of existing ancient stories which would give insight even into the stories of God? A clue to this can be in terms of the dialogical spectrum of (dis)connectedness, where the aim is not to ascertain where children should be but rather discover where they think they are, and where they would like to be. This moves away from the authoritarianism of institutions such as the hospital, liberating children from the isolation of their new world as connectedness can unlock the imagination of the stories they tell about themselves.

In an exploration of the needs of children in hospital, Hauerwas referred to Bluebond-Langner's study of the effects of "mutual pretence". Mutual pretence involves adults censoring what children need to know about their medical condition, and takes place in a repressive culture (Bluebond-Langner cited in Hauerwas, 1991, p.126).<sup>316</sup> Pfund notes that these "attempts of keeping children blissfully unaware therefore masks a child's suffering leaving them to cope alone" (Pfund, 2000, p.145). Hart and Schneider indicate their concern about this repressive culture when they say that "due to parental and adult discomfort of discussing issues of death, children may ask questions to test adults to determine their willingness to talk about death (Sommer, 1989, p.232; Stuber and Houskamp, 2004, p.133). They test to see how honest, open and non-judgmental the adult will be" (Hart and Schneider, 1997, p.265; Hufton, 2006, p.245). Bluebond-Langner's study of children dying of leukaemia reveals how children are forced into a mutual pretence by parents and doctors to behave as if they were going to live when they were actually dying. The narrative of their lives was being conditioned by parents unable or unwilling to offer a protective role. However, the children felt free to speak when they met with each other in a shared bathroom and in doing so, created a means of connectedness for sharing their secrets. They found a way to tell their stories to an audience prepared to listen and accept (Hauerwas, 1990, p.131)<sup>317</sup>. However, the sad irony of Bluebond-Langner's study is that despite the fallacy of this adult approach, the children found their 'subversive' behaviour had a therapeutic effect in their short lives. They created their connectedness through friendship; through relationships that were honest and supportive. The children's resourcefulness enabled them to find a way to articulate their connectedness, although in a place of isolation. Connectedness, understood in the context of a SAT, seeks to create a place which all can draw meaning from the creation of data; the child, assessor and those beyond the encounter. However, a question which remains unanswered is "can a healthcare setting respond with care appropriate to the information shared by a child?"

A similar question may arise for institutions of faith that have adopted a repressive approach; institutions that are fearful about how to nurture followers who may struggle with doubt, or question their chosen stance on lifestyle. What would be the subversive means for these followers to find connectedness between themselves and what they believe in as an

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<sup>316</sup> Bluebond-Langner's report on oncology camp documents how children valued peer support and demonstrated the contrasting picture reported earlier by her (1991, p.75).

<sup>317</sup> This is in Bronfenbrenner's terms a dyadic link being formed.

identifiable link in their solidarity with others in a similar plight? The tragedy being that this repressive approach leads to isolation. In the process of using a SAT a dialogical contract is engaged in, through which it is possible to know what people are, rather than what they should be. However, as already demonstrated, this must take place in a secure context of mutuality.

Connectedness is a relational act. A person's internal dialogue of connectedness forms the embryonic stage of rehearsing thinking in order to engage with wider surroundings (Ward, 2005, p.89). Play is an externalizing act of connectedness. The effect of using a SAT in the encounter between child and assessor is to accelerate internal dialogue and enable the child to express how his/her sense of connectedness is formed. For the interpretative framework of connectedness in this project to be useful, the assessor must introduce a projected world using the sorting cards and storyboards. This will allow the children to expand their internal dialogue and share information about their life from their perspective. Children need to work in a setting where they can express their current reality and relate to other contexts from their present one.

The articulation of the connections generated by the child is then translated into the world of the listener. Thus the child is making a connection, not just with an individual, but with a group of people who are able to share in that connection through the sharing of information from the SAT. We must ensure that this connection has been made by the giver of the information; the child who is sharing through story and play. It is what Lynne Pearce refers to as "an instrument of communication that can only function through the interaction of two people" (Pearce, 1994, p.2). Interacting through the SAT provides the means for expected dialogue to take place. This interaction, understood through the concept of connectedness, provides an epistemological grounding to our existence and the reconstructing of a material reality<sup>318</sup> (Voloshinov, 1973, p.11). There must be active participation between the assessor and child for connectedness to be identified; it is not only through word, but by visual choices that an identifiable link is created where meaning is constructed. The selection of a sorting card is an "utterance"<sup>319</sup> made by the child of what is important to her while she is in hospital.

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<sup>318</sup> A theory of the production of knowledge

<sup>319</sup> " 'Utterance', according to Holquist (Dialogism, p.60), is 'the fundamental unit of investigation' in Bakhtin's work." (Pearce, L.; Reading Dialogics, p.3, 1994, London)

The dialogic principle refers to the voices heard in the encounter; that of the assessor and the paediatric patient. The findings, and their meaning, are the outcome of interaction between them during the SAT. Within the content of the conversation between the assessor and child there is both connectedness and disconnectedness. The meaning is between these two dialogic positions and in how the assessor and the child relate to each other; the sense of connectedness or disconnectedness which they convey to each other.

It is acknowledged that the encounter of connectedness established is explicit about where the power balance rests in a dialogue between an assessor and a child; connectedness provides a means to understand the balance of power between individuals. This is why it is crucial that the competences described in Chapter 8 retain the balance of power, so that there is an interaction where the child feels able to portray an identity which assists healthcare professionals to deliver appropriate care. Connectedness requires a dialogic contract which integrates the skill base as part of the encounter, so that the assessor understands the balance of power in aspects which may be subconscious or subliminal. This is achieved by acknowledging that connectedness is part of a new language. An assessor must have a self-awareness of what it means to have connectedness (illustrated in Chapter 8 Section C.4).

Features of play and freedom are what I seek in my encounter of connectedness with a child. Frances Ward's insight into the dimensions of play in the context of supervision with adults enabled her to rediscover the creativity needed to work in ministry. She let this form of encounter permeate her understanding of humanity and her understanding of God (Ward, 2005, p.88). Ward bases her model of supervision on the idea that culture and religious activity are extensions of a person's playful engagement in understanding the reality of the world. Similarly, the interpretative framework in this thesis incorporates connectedness at several levels; through the design of the tool and the assessor's competency to engender a ZPC encounter. It is an invitation to consider what it means to have an encounter with God.

Ward says of Winnicott:

“His observations of small children led him to see play as an activity that enabled a child to engage with external reality and, in the right facilitating environment, to experiment and explore their sense of self in the world” (Ward, 2005, p.89).

Ward uses the term, “playground” which is a powerful image of childhood freedom within a context where there is a measure of responsibility for the safety of a child. The form which connectedness takes in a child can be different to that found in a fully developed adult. Heyward refers to this development in Kwok and Soelle’s work as a “form of freedom” (1999, p.49). Both Ward’s work and this thesis put forward an expectation that a certain quality will be present; otherwise a person’s functioning humanity will be deeply affected (Ward, 2005, p.88).

Ward argues that this aspect of an individual’s sense of self awareness continues to develop in adulthood and that culture and religion offer “the playground” for this exploration to happen (Ward, 1982, p.53). Using the SAT with children provides a “playground” environment within which to explore the reality of their environment and make sense of the hospital world. However, this feature of self awareness is developed further using the ZPC which makes explicit the intimate nature of playfulness, which I would term an expression of connectedness. Such an intimate place is an area of vulnerability and so the assessor must ensure that the encounter is a hospitable place. In the later stages of this research this hospitable context was improved as the contextual setting was more limited. In order to preserve this hospitable space, staff need to be supportive and protective by allowing no interruptions. The assessor and the child must commit as partners in the encounter, to allow for a greater freedom.

If play is a universal activity, and connectedness is the explicit expression of its intimate nature, then an encounter which yields such behaviour is reaching into an intrinsic feature of our humanity. It is a means by which we can relate to each other. The rituals encountered in religion (such as the sacraments in Christianity) can enable a safe environment to explore who God is in relation to us. Ward explores this aspect by referring to Taylor’s work and his description of ‘the go-between God’. Taylor, writing from a western perspective in the 1970s, refers to the rediscovery of the place and work of the Holy Spirit in the life of the church. Ward picks up from Taylor’s work the dimensions of this discussion which are consistent with Winnicott’s theory of the intermediate place of exploration; that the revealing of a person’s intimacy in a public setting requires safe and secure structures. If an expression of a child’s intimate nature is applied to connectedness, then the links that a child establishes as a basis for meaning are critical points of identification. This is particularly so if these links are points of disconnectedness.

Ward notes that:

It is the generosity of Taylor's go-between God that is attractive here: the sense in which with such a God it is possible to go the extra step that makes dialogue work (Ward, 2005, p.98).

Play activity is consistent with the format of the SAT, which uses a physical, intermediate play-space in which to engage with the child and engender an inclusive and mutual dialogue. Ward, reflecting on Taylor's work, develops further the principles through which he understands how God relates to us, where there is openness to an inclusive or mutual dialogue. What is being explored here is not only a human quality but the nature of encounter between people. An environment containing a "playground" allows for the disclosure of identity, whilst still being a place of responsibility. The boundaries of the encounter in other contexts are outside the remit of this thesis, but here there is a clear indication that mutuality is an integral aspect of the encounter.

Taking the Christian narrative as an example, the qualities required for mutuality might provide insight into a concept of God and lead to a reconstruction of a belief system which changes our understanding of God, Jesus and the Church (Wong-McDonald and Gorsuch, 2004, p.332). The form that this reconstruction takes is unpacked by Ward when she explains that by "placing ourselves in their position (we) can ... begin to communicate across the gulf of otherness" (Ward, 2005, p.99).<sup>320</sup> If this communication is to work through play, then there must be an equity which requires a kenosis; an emptying of one's self. The assessor must know how to play with the child in a way that involves an equal partnership in an exploration of connectedness. A true assessment in play would constitute openness on the part of the assessor to allow children to feel that they are engaged in a dialogue.

If the assessor allows the child to have a sense of being an equal partner, and has openness to the child's world, how should that be understood in the context of a person relating to their God? If there are playful attributes within an individual, further consideration is required of the playful way in which individuals might relate to their image of God (Dickie, Eshleman, Merasco, Sherdard, Vander and Johnson, 1997, p.25; Eshleman, Dickie, Merasco, Sherdard,

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<sup>320</sup> This relates closely to the dialogic principle that connectedness acts as a bridge of communication. It also is part of the liminal skills required by the assessor discussed in Chapter 8.

and Johnson, 1999, p.145; Melchert and Proffitt, 1998, p.23; Burke, 1999, p.10). We relate to another in dialogue, knowing that there has been a voluntary divesting of power to ensure there is mutuality. Does this suggest that if we are to encounter God, there must be a divesting of power by both so that mutuality can be present in the meeting between God and us?

The encounter through the SAT does not only encourage play, but also encourages the construction of story. This requires other models of theological reflection to be applied. In the chapter entitled, “Speaking in Parables: Constructive Narrative Theology”, Graham et al. (2005) explored a model of theological reflection that focuses on the conveyance of information through telling a story, and offers further insight into the use of story in a SAT. Their model allows for exploration into the means of gathering information by exploring the premise that *story* is an accessible means for a child to share information. While the child’s story will have its own reference points, the focus in this research is to understand how to frame these narratives to understand what is happening to children during their healthcare journey. The interpretative framework of connectedness within a child’s story can point to the fourfold dimension of (dis)connectedness. One person tells the story, another interprets it in order to convey it to yet another; this becomes a “sacred” process of knowing what this information means and what is required in response (Graham et al., 2005, p.49).

Here, the nature of connectedness is brought about by story. The child’s stories are constructs which reveal the connectedness of that child. There are several dimensions to this storytelling. At its basic level, it is the gathering of information in advance of the healthcare journey which may then be used in a pre-emptive way; while other stories told by children in hospital may be redemptive. Telling the story may be therapeutic, although this is not the primary purpose; the story is a way to facilitate the giving and receiving of information in a manner that is safe and comfortable for the child (Graham et al., 2005, p.66).

There is a point reached in the storytelling where the storyteller feels at one with the story, and the listener (the assessor) is at one with the story being told. This may occur in several ways; the child’s perspective might change; the assessor’s understanding of the child’s (dis)connectedness becomes clearer; or it might be that the assessor is able to anticipate how such information can enable improved care for the child (Graham et al., 2005, p.75). It is in the quality of the storytelling which both believe together that the story shared and listened to

will create change; the committed involvement of assessor and patient to the story told in the encounter can allow information to be revealed about the child that can be used by the assessor to powerful effect to provide patient centred care.

Graham et al. state that:

There is ... a narrative quality to all ritualizing and storytelling is given depth and profundity through its association with ritual practice (Graham et al., 2005, p.68).

A SAT seeks to tap into the elemental nature of storytelling. This relates closely to Ritual Process Theory which has within it an element of what Myer's refers to as "transcendence", which was applied to the ZPC in Chapter 7 (Myers, 1997, p.79). The ZPC is where children let their story flow and demonstrate a sense of (dis)connectedness through their *awareness* of connectedness. The assessor is in a privileged and responsible position in receiving such information which is at one level whether it is described as "sacred" or "privileged information" or a "newly disclosed identity". To pass on such information without respect is to devalue, indeed to desecrate, the "sacred" level of trust which the child has displayed.

One of the challenges of this research has been maintaining the ethical boundaries of storytelling in the context of a healthcare system<sup>321</sup> which seeks to preserve the safety of the individual. It is the responsibility of the researcher to ensure that no harm comes to any child participating in the project. This has been upheld throughout the research, and while certain potentially unsettling themes have emerged, such as bereavement, violent revenge and relational breakdown, no distress was expressed during the interviews. Were disconnectedness to be manifest through a child's distress, certain narratives might have to be omitted. An assessor must know how to approach traumatic narratives explored by children,

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<sup>321</sup> Ethical requirements meant that parental publicity literature for this research included certain reassurances. This is one example of a question from the Parent information leaflet, "Are there possible disadvantages in my child participating in the study? It is unlikely there will be any disadvantages. However, there is the slight possibility that your child might become distressed when telling their hospital story. If this was to happen to your child, the interview would be stopped and you or a member of staff would be called immediately to comfort your child." This was never required as Docherty and Sandelowski suggest, (Docherty, Sandelowski, 1999, p.180)

related to areas such as child abuse or psychiatric disorders which are not immediately therapeutic or, more poignantly, what Walton calls poiesis<sup>322</sup> (Graham et al., 2005, p.71).

The encounter of connectedness offers insight into the dynamics of what could be involved in understanding how a person might describe an encounter with their God. This thesis has raised questions beyond its initial remit and the next section, on the context of connectedness, is an exploration of areas which warrant further research. Can the model of encounter within which meaning is discovered and constructed form the basis to understand how encounter in other contexts can be explored and better understood?

#### *4. The context of connectedness*

Limitations have been placed on the structure of the interpretative framework of connectedness within this project, in order for it to be applied to a specific context. However, this deliberate narrowing of the scope of the data sought also offers insight into the possible implications for other contexts. It is necessary to take a broader approach to address the challenge of the vernacular theology of connectedness.

The challenge for a contextual theology of connectedness is the extent to which it can relate to other contexts beyond its initial application. In order for it to be fit for its particular purpose, the interpretative framework of connectedness developed in this thesis, and particularly its four dimensions, has been closely allied with aspects of child development. The localisation of the framework is deliberate to ensure it can be applied in a context where specific information is sought. It offers a level of existential insight that has the capacity to protect the child from being misunderstood. Even though the SAT is being used in a specific context, it may be useful to provide a process and a series of questions which enable connectedness to be explored in any other given setting.

As Graham et al. state:

Local theology thus seeks to be a conduit by which some of those expressions might be realized: the values of a culture, its focal images, its social ills and problems, codes of conduct, habitats and customs, cultural and political patterns and institutions.

(Graham et al., 2005, p.216)

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<sup>322</sup> Poiesis is a narrative where there is no apparent plot but a context to hold the chaos of what is being told.

The specific nature of the context in which the study took place may challenge the transferable nature of the concept of connectedness, but it addresses the need for clarity within that context. While there might be a concern that this theological reflective model has lost “the homogeneity of Christianity” when it is applied in this thesis, this is actually a strength, as the concept of spirituality has already lost its applicability in the setting of the NHS. If healthcare chaplains do not wish to relinquish spirituality as the predominant term to describe spiritual care, this may indicate a desire to be in control and this could deny the mutuality required to fulfil their role.<sup>323</sup> Exchanging the concept of spirituality for that of connectedness has overcome both these difficulties. Is a term required, other than connectedness, which is appropriate to other contexts? What is transferable to other settings from this thesis?

There are components in this thesis which are combined in a particular context; sick children, family members, a paediatric hospital, a healthcare chaplain, interviews, a SAT portfolio, a research process<sup>324</sup> and the NHS system in the Scottish context. However, some of these components are common to other healthcare settings. As such, the question to be asked is “what is the experience of connectedness in the encounter with others which informs pastoral theology?”

Is it possible that a theology of connectedness developed in a secular context could be transferred to that of a faith community, potentially to help members to understand the connectedness of their children to their own tradition? I refer to a faith community as it would appear that a generation is emerging which may be described as being ‘disconnected’ from its faith community (see Chapter 1). It would be useful to attempt to understand how a faith community relates to the children who are part of it, and the way the community views the nurture of children and how they connect to their surroundings. Questions could be asked such as; “Do children have a sense of empowerment in the way they construct meaning? Are children able to engage in a dialogic process as they construct meaning through the narratives and belief systems that are part of their upbringing and faith community?” These questions

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<sup>323</sup> During the presentation of this chapter to the national conference of the Association of Palliative Care Chaplains in May 2012 there was during the question time a concern by some to relinquish the term “spiritual” to be replaced by the term “connectedness”.

<sup>324</sup> This component in itself contains the ethics committee, the university supervisors, the consent from consultants and the ward staff.

address how children might describe their identity, their encounters and the language that helps them understand the tenets of their faith.

An understanding of the connectedness of children in faith communities could contribute to an understanding of how the connectedness of children is developed and how they construct their beliefs. Indeed it could contribute to an understanding of how their sense of connectedness relates to the wider world. These communities may need to consider how their members construct meaning, how they are to arrive at their sense of identity, and how they would decide when an encounter had reached a ZPC.

A number of questions arise in relation to the transferable nature of the concept of connectedness. What could be learned concerning a child's connectedness in the context of a faith community? Does a child's story in a hospital context resemble the stories narrated in a faith community? This thesis is concerned with providing a respectful place for children to contribute to their own sense of connectedness in healthcare. Can this be repeated in a faith community? What place are children given in other contexts such as faith communities or educational establishments? Are children able to share about their experiences of how such places affect their sense of connectedness? Has a child's connectedness been rediscovered through this process? If this new concept allows a clearer understanding of children in this context, does the concept of connectedness transfer back into the religious context? Is there a way to understand children better in a religious setting; one which encourages those nurturing children's spiritual development to consider connectedness as a framework for a child to construct a sense of meaning within a faith setting? The application of the conceptual framework and process would ascertain the authenticity of a child's status within such a community and offer insight into how children construct meaning through the dyadic links they have within such a community, and indeed those they make outwith their faith community. For example, if an attempt was made to understand how children viewed their place within a faith community, then applying Bronfenbrenner's concept of a dyadic link may help to determine what that might be in a faith community.

The Rev. Albert Bogle, moderator of the General Assembly of the Church of Scotland, noted the problems related to how a faith community relates to each other when he stated in an interview in 2012 that:

We are living in a paradoxical society where we are disconnected yet ever connected, we need to understand church in a different way. We need to be relational, meaningful, and discover connectedness in a variety of different ways (In IDEA magazine, 2012, p.24).

The questions above relate to aspects of community or, more specifically in a Christian context, to ecclesiology. But ecclesiology often derives its structure from a community's view of God and, in the case of Christianity, Christology, which draws from biblical narratives to inform such doctrinal frameworks (Bradbury in Woodward and Pattison (eds.), 2000, p.173). One theologian who spoke of connectedness and community was Dietrich Bonhoeffer. In his book "Life Together" he uses the Christian story of Jesus to understand why the church and faith community is connected and he identifies the important role of communion, and how as a ritual it should be a space where we need to readdress and reconnect with other to be a unified church. Theology provides a reference point to help view what is hoped for and what is already present (Bonhoeffer, 1954, p.87).

These explorations above can be extended to look at a child's sense of connectedness in relation to God. Is it possible to explore further how this would link our construction of meaning to God? If the concept of spirituality has been replaced by one of connectedness, how can God be understood through this new framework? Is the nature of encounter in the faith community one which empowers children within it to be free to develop, and where their sense of connectedness will be understood?

There are several approaches which children could be encouraged to adopt in storytelling in order to develop their sense of connectedness. They may tell the story that arises out of their experiences or they could retell a sacred narrative and the researcher would infer their sense of connectedness in relation to the belief system they are a part of. This study has adopted the former so that the child's understanding informs the assessor's perceived understanding of his place of work. Can the dynamic of this connectedness, once adopted by a faith community, inform the secular and professional context of a healthcare chaplain? Could the concept of connectedness be a means for a healthcare professional to introduce values to shape the child's attitude towards their health? This may be a crucial consideration as the main focus of this thesis has been diagnosis, not therapy. To consider the therapeutic nature of connectedness, it would be necessary to explore means of therapy to improve a child's sense

of connectedness. The criteria to create such values, if clearly and appropriately worked through, could support children who may need to cope with their illness, not only in a healthcare context, but in the wider community.

This introduction of values heightens the accountability of professionals caring for children where they are able to explore aspects of transformation within the context of a theology of connectedness. In effect, it is a contextualisation of our understanding of God. The aim of any discussion would be to indicate how we can care for and communicate with others with different views through connectedness. A pertinent phrase here in terms of the direct metaphorical connection is, “made in the image of God” when it is applied to a human being (Newlands, 1994, p.95, 384). Newlands states that:

essential to human nature itself is the God-given drive to relate  
(2006, p.384).

This doctrinal statement suggests a connectedness between our understanding of God and ourselves as human beings. Whether or not we acquiesce to a person’s viewpoint, the use of connectedness as a framework enables people of differing beliefs to understand each other’s concept of God, and to understand how that brings meaning to their life.

What is the image of God in relation to a theology of connectedness in terms of our language, identity, encounter and context? As defined at the start of this chapter “connectedness is the identifiable link where an individual or another constructs meaning”. Connectedness does not prove the existence of God, but it does relate to how people’s views of God exist in their construction of connectedness. It identifies not just an image of God, but also the links from which that image is constructed. This would indicate the extent to which people’s beliefs are integrated in relation to their concept of the nature of God. In Bronfenbrenner’s terms, it would map the dyadic links between the systems where their God could be identified.

If the concept of connectedness was applied to the image of God, it might be possible to observe an internal dialogue which relates to an image of a “divine being”, where people converse within their construction of meaning with an image of God distinct from their own perceived identity. An interpretative framework of connectedness could be used to explore the robustness of such a dialogue by relating the image of God to the dyadic links within a

person's awareness of connectedness. Therefore, when related to the encounter of connectedness, the person's understanding of God could be explored at different levels.

This thesis has shown that the understanding of meaning takes place within the encounter. It is the combination of the location of the encounter, those involved in it and *how* the encounter takes place that presents the construction of meaning. People's projection of their construction of their concept of God is significantly informed by the encounter. Just as play and storytelling were accessible means to constructing meaning, so there may be other means that enable the construction of meaning that can be projected and shared with others. It would be interesting to explore the encounters in a worship service, rituals administered, pastoral support and church programmes, and to consider how these contribute to a person's (dis)connectedness.

The nature of the encounter and the way it constructs meaning in terms of God can be informed by the Zone of Proximal Connectedness (ZPC), with particular reference to how the ZPC relates to the robust nature of a person's cognitive style, or the resilience of connectedness. The theology of connectedness can be used to explore how people respond to a new disclosure of identity. In this thesis, I have sought to address that dynamic in a professionally safe and responsible environment. The ZPC could be applied in a faith community and the nature of that encounter might lead to the construction of a different meaning and understanding of God. A faith community could seek to understand how people have constructed their meaning of God by exploring the encounters which they have experienced with faith leaders or teachers. This might give insight into the boundaries that should be in place in the exploration of meaning.

Further consideration should be given to how the context of connectedness can be applied to ascertain whether particular factors addressed in this thesis could be relevant in other contexts of care. A theology of connectedness could be used to explore how a "Christology of connectedness" would enable those who have a Christian faith to understand how they can work through their beliefs. In her book, *Saving Jesus From Those Who Are Right*, Carter Heyward refers to the "dialectically dynamic interplay" that allows a person to relate their social and personal perspectives. Heyward's project sought to overcome the individualisation of Jesus, and the plethora of meaning and definition given to the person of Jesus that diverts

from the significance of the mutuality of the concept of Jesus. Drawing from “Eurocentric philosophies” (Heyward, 1999, p.38) Heyward states that:

my understanding of everything important – including the aims of feminism, the work of liberation, and the ground of theology – has been refreshed by a spiritual intuition and assurance that everything is truly connected, that we really are part of one another, and that each of us actually can draw strength simply from knowing deep in our souls that we are not alone (Heyward, 1999, p.43).

Heyward refers to Macy’s work on “dependent co-arising”<sup>325</sup> (p.229, Heyward, 1999). She uses this as a means to readdress the concept of who Jesus is so that a renewed form of existence, and therefore our perception of the world, is informed by a different understanding of Jesus. In this context, connectedness provides an appropriate new emphasis for our existence not only to inform and improve practice in the healthcare setting, but in order to introduce a new perspective to look afresh at existing and assumed points of reference. Connectedness recovers a perspective which the term spirituality has lost; the perspective of cohesion. Spirituality tends to veer to “autonomy” while connectedness gravitates towards “mutuality.” Spirituality is used to describe a vast range of phenomena, but its use results in an increasing individualisation as those who use the concept describe their lives by selecting from an array of definitions. The use of connectedness instead facilitates a move away from individualisation to a more collective understanding, which requires accountability and responsibility; it identifies features through a terminology which people can comprehend and engage with. It is not centred on the person as self, but is centred on the person in context and encounter. The concept of spirituality is concerned with existence; the concept of connectedness is concerned with community. This concern with community does not entail coercion to conform, but acknowledges cohesion within our diversity so that there can be a means of understanding between different communities. Heyward refers to “the radical connectedness of all reality ... our moral work as human creatures is to notice this

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<sup>325</sup> “dependent co-arising” is a Buddhist teaching that refers to the interconnectedness as creatures. In applying this concept it builds on the concept of connectedness and how our institutions and construction of language can be related to how we are towards each other. If such meaning and organisation of society has been constructed in such a way that it is adversely affecting those who are a part of it and are powerless to change it then there is an onus on those to transform the current state of affairs to take into account those that are vulnerable and marginalised.

connectedness” (Heyward, 1999, p.62)<sup>326</sup>. However, this moral imperative implied within the concept of connectedness has not been addressed in this particular thesis.

### **Chapter Conclusion**

The language, identity, encounter and context of connectedness have been the building blocks for a theology of connectedness that offers a theological reflective model of understanding for use in a variety of settings. Understanding is achieved by creating a language which addresses the responsibility of the professional to care for others in a healthcare institution. Those who use a contextualised theology are required to acknowledge the limitations of their framework. The mutuality of connectedness engenders the integrity of the encounter with an open and inclusive attitude, which offers a secure environment and avoids the assumptions engendered by more traditional terminology. If spirituality is a maze, then connectedness is a map.

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<sup>326</sup> This lies at the heart of my own rationale for developing a new form a church that enables my community to notice their need for connectedness.. Further information is on [www.westmearnschurch.org](http://www.westmearnschurch.org)

## **My conclusion and my hope**

At the start of this thesis a question was posed: What insights are gained from the use of a portfolio of spiritual assessment tools with hospitalised school-aged children, to facilitate the delivery of spiritual care offered by the healthcare chaplain? The research undertaken to answer this has resulted in five significant insights.

The first insight emerges from the necessity for a clear, accessible, conceptual construct in order for an assessment to be made. Identifying and developing the conceptual construct of “connectedness” has resulted in a new approach to describing the nature of childhood spirituality in a paediatric healthcare setting.

The second insight stems from refining the design of the spiritual assessment tools used in the research. The tools increasingly became focused on enabling children to share their perspective on their lives during the healthcare journey, and thus provide information with direct relevance to the care provided. In relation to the delivery of care by healthcare chaplains the design of the tool created ensured that a child felt safe and supported, and the chaplain felt able to conduct the assessment in a consistent way with their style of work.

The third insight emerges as a result of the identification of the specific competences required for a healthcare chaplain to conduct the spiritual assessment tool. The competences required were identified as being hospitality skills, liminality skills, reflexivity and connectedness skills. This fourfold skill set was based on accepted competences within healthcare chaplaincy. However the significant forward step made by this thesis is the combination of this skill set with the above methodology; leading to the encounter between patient and healthcare chaplain being conceptualised as the Zone of Proximal Connectedness (ZPC). The ZPC provides a foundation for a clear and integrated theological reflective practice framework which relates to connectedness. It provides healthcare chaplains with the opportunity to standardise their range of practice from assessment to informed intervention, in a way that is consistent and transferable.

The fourth insight is concerned with theological discovery, and stems from an understanding that professional responsibility depends on information presented by the patient. Therefore, the ZPC and the conceptual construct of connectedness offer a new perspective into how to

describe a person in terms of connectedness. As a Christian theologian I consider that a new perspective on the doctrines of God, Christology and Ecclesiology may reveal further possibilities of how the concept of connectedness can describe the functional nature of such beliefs.

Finally, the idea behind the initial question has worked. The desire to empower children so that their voices could be heard and their rights upheld. My conclusion is that my research has made that more possible than it was before.

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## **Appendices**

1. Summary of Masters Dissertation
2. Research Literature
  - a. Information leaflet
    - i. Parent
    - ii. Child
  - b. Consent form
  - c. Preparatory Questionnaire
  - d. Letter of consent from Consultant
  - e. Flyer/poster
3. The Logistical Process for setting up an interview
4. List of Technical Equipment for Research
5. Summary Data of Case Interviews
6. Case Study Summaries
7. Child Development Table
8. Thesis outline at December 2010
9. Pictures
  - a. Storyboards
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## **Appendix 1:**

### **Summary of Masters Dissertation**

The Masters dissertation sought to address the current thinking found amongst health practitioners who are concerned about the delivery of a spiritual care within the paediatric context. This was particularly concerning the definitions of basic terms used, such as spiritual care and spirituality. The reason for this focus was that healthcare practitioners have the biggest impact upon the delivery of spiritual care, whether that be in identifying existing good practice in this field or by offering recommendations to address the spiritual needs identified. The paper addresses how such understanding can affect the spiritual care of one of the most vulnerable sectors of society, that of sick children. The paper draws attention to the need to be committed to a spiritual care agenda by healthcare professionals would enable their paediatric patients to come through a critical stage in their life. The outcome for children could be to use their healthcare journey as a spiritual experience, that can be applied in a healthy manner, to the rest of their lives. The paper unpacks that if these issues are not addressed properly, we could end up espousing a misguided and misinformed understanding of spirituality and deliver a spiritual care that may be detrimental to the well-being of the child. This could leave a child confused, distressed and neglected through an inexcusable professional paternalism, where the healthcarer presumes on what they consider best for the child. The paper identifies that healthcare professionals who have published material, admit that more work is necessary in looking at how the research material is generated and assessed to see if children, within a research context, speak for themselves in broader spiritual terms, as proposed by NHS Scotland. The paper proposes that research needs to be commissioned that credibly reflects the views of children within hospital in the Scottish context, so that a delivery of a spiritual care service is truly patient centred. If this can be achieved, then there is hope too for the spiritual care of children in other sectors of society and the institutions that serve them.

## Appendix 2: Research Literature (a) (i)



# Research Study Project

Spiritual Assessment Tools  
for Hospitalised School Aged  
Children

Parental information leaflet

### Who is organising and funding the research?

This research is organised by a research team

Rev. Alister Bull, Head of Chaplaincy Services

Dr. Heather Walton, Lecturer, University of Glasgow, Department of Religious and Theological Studies, serving in a consultative role

This project has been reviewed by the Research Ethics Committee

### Funding

To be confirmed

### What if I'm unhappy about the research my child took part in and I want to complain?

If you have a complaint about what has happened to you in the research please contact:

Kate Colquhoun  
Complaints Officer  
Yorkhill,

Dalmair Street, GLASGOW, G3 8SJ

Tel: 0141-201-9278

[e-mail: kate.colquhoun@yorkhill.scot.nhs.uk](mailto:kate.colquhoun@yorkhill.scot.nhs.uk)

### For further information please contact:

Rev. Alister Bull  
Chaplaincy Office,  
First Floor, Queen Mother's Hospital,  
Yorkhill NHS Trust,  
Dalmair Street,  
GLASGOW  
G3 8SJ

Tel: 0141-201-0595

Internal Ext: 80595

[e-mail: alister.bull@yorkhill.scot.nhs.uk](mailto:alister.bull@yorkhill.scot.nhs.uk)

## Appendix 2: Research Literature (a) (i)

<p>You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.</p> <p><b>Frequently asked questions . . .</b></p> <p><b>What is the purpose of this study?</b></p> <p>The purpose of this study is to find out what insights can be gained about the spiritual needs of hospitalised school children by using spiritual assessment tools in the form of story books and picture cards.</p> <p><b>Why have you and your child been chosen?</b></p> <p>There are three reasons. First of all, your child is staying in Yodhill Hospital. Secondly, your child is in the age range of 6 to 13. Thirdly, your child will be one of twenty children randomly selected by our chaplain.</p> <p><b>Do I and my child have to take part?</b></p> <p>No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you belong to a particular religion you may wish to seek advice from your religious</p>	<p>leader. The Chaplaincy department can assist you in making contact with them.</p> <p><b>What will happen to my child if he or she takes part?</b></p> <p>Your child will be shown four pictures and asked to tell a story of a child's stay in hospital. The chaplain will ask questions that will help your child to focus on the spiritual needs of the child in their story. This story technique will show the spiritual needs of the storyteller (your child). This would take place either at the bedside or in a room in the ward. The story your child tells will be recorded. The visit by the chaplain will last 45 minutes to an hour.</p> <p><b>What do I have to do?</b></p> <p>There would be four requirements expected from you. First of all, if you are willing for your child to participate in this research study, we would ask you to sign a consent form a day later from receiving this leaflet. Secondly, you will be asked a few questions by the chaplain. The answers to these questions will help the chaplain decide whether or not your child would be involved with the study. If the chaplain's decision is not to continue the study with your child, this due to the limits of the study and not a reflection on you or your child. Therefore, the answers to the questions will decide whether or not your child continues with telling the story board and picture cards. Thirdly, on the successful completion of the questionnaire the chaplain will arrange an appropriate time to meet with your child on their own. Fourthly, the chaplain will return to share what we have found out from your child's story. If you have left the hospital we shall contact you at your home address by letter.</p>	<p><b>Will my child's details be kept confidential?</b></p> <p>Yes. The research would work in compliance with the Data Protection Act 1998, in regards to secure storage and identification of information given by your child. The information would be anonymised and a study number would refer to your child.</p> <p><b>Are there possible disadvantages in my child participating in the study?</b></p> <p>It is unlikely there will be any disadvantages. However, there is the slight possibility that your child might become distressed when telling their hospital story. If this was to happen to your child, the interview would be stopped and you or a member of staff would be called immediately to comfort your child.</p> <p><b>What will happen to the results of the research study?</b></p> <p>We will listen to and write out your child's story and identify common ideas that emerge from the way the story is told by your child. These themes include the child's emotions, behaviour and ideas about their meaning of life and God. We would inform you of the overall findings of the study. However, any specific details of your child's contribution can only be given with your child's consent. These areas will be compared to general literature about the spiritual care of children in the healthcare context. The results of this study will hopefully be published in a healthcare and Chaplaincy journals.</p>
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## Research Study Project

How playing games and stories with a chaplain can help a child's hospital stay.

Spiritual Assessment Tools for Hospitalised School Aged Children

**What if I want to find out more about the research?**

You can speak to:

Rev. Alister Bull,  
Chaplaincy Office,  
First floor, Queen Mother's Hospital,  
Yorkhill,  
Dainard Street, GLASGOW G3 8SJ  
Tel: 0141-201-0595  
Internal Ext: 80595  
✉: alister.bull@yorkhill.scot.nhs.uk

**Who is organizing this research?**

These are the names of the people in our team

Rev. Alister Bull, Head of Chaplaincy Services  
Dr. Heather Walton, Lecturer, University of Glasgow, Department of Religious and Theological Studies, serving in a consultative role

**Where does our money come from?**

To be confirmed

**How do we know this work will be carried out properly?**

There are two groups of people who will check our work. One group from the University of Glasgow and the other group is the Research Ethics Committee who has allowed us to do this work in the hospital.

**What if I'm unhappy about the research I took part in and I want to complain?**

If you have a complaint about what has happened to you in the research please contact:

Kate Colquhoun  
Complaints Officer  
Yorkhill,  
Dainard Street, GLASGOW G3 8SJ  
Tel: 0141-201-9278  
✉: kate.colquhoun@yorkhill.scot.nhs.uk

Patient Information Leaflet

## Appendix 2: Research Literature (a) (ii)

<p>A chaplain is asking you if you want to help us find out a good way to help children's spiritual needs in hospital. Grown ups use the word spiritual to help us think about what makes us feel good. ☺☺☺☺☺☺ happy inside. This leaflet will help you decide.</p> <p>You can ask us questions and talk things through with your parents or other people who help you make important decisions. These are the questions other children and parents have asked us.</p> <p><b>What is a chaplain?</b> It is someone who works in the hospital. The chaplain cares for families and children because they believe everyone in the hospital is special.</p> <p><b>Why do we want to find out about a good way to help find out the spiritual needs of children?</b> We want to know from children, what they think about their stay in hospital. There are some ideas we are really interested in. We want to find out what makes you feel good, brave and happy inside. This is what grown ups call spiritual need.</p> <p><b>Why have you been chosen?</b> There are three reasons. 1. You are staying in Yorkhill Hospital. 2. You are aged from 6 to 13 years old. 3. You are one of twenty children the chaplain has asked to take part.</p> <p><b>Do I have to take part?</b> No, it is up to you, whether or not you want to help. If you do help you can keep this information sheet. You are allowed to change your mind at any time and say you want to stop.</p>	<p>You do not even have to give a reason. No one in the ward will feel bad about it. They just want to make sure they are caring for you in the best way possible.</p> <p><b>What will happen when I take part?</b> The chaplain will show you story board and picture cards and ask you to tell the story about the people on the picture cards. The chaplain will then ask questions that will help you think about the spiritual needs of the child in the story. It is not a test.</p> <p>This story telling can give us a good idea of the best way to care for you in hospital. This visit will take place either at your bedside or in a room in the ward. The story you tell will be recorded and filmed. The visit by the chaplain will last about 45 minutes</p> <p><b>What happens first?</b> If you want to take part the following things will happen. 1 The chaplain will ask you to sign your name on a consent form the day after from getting this leaflet. This tells us that you have agreed and understood what you have been told. 2 The chaplain will ask your parent or carer a few questions. The answers they give will decide whether or not you can take part in the study. 3 The chaplain will come back another time to meet with you on your own. 4 The chaplain will share with you what we have found out from your story. If you leave hospital before this happens, we will need to use your</p>	<p>name address to tell you. <b>Will my name and details be kept secret?</b> Yes. There are laws we have to obey. They make sure your name in this study is kept a secret. This is called the Data Protection Act 1998. This makes sure you are very safe and no one will find out the study is about you. We do that by replacing your name with a Number. We then make sure all the details about you in our study are put in a locked cupboard.</p> <p><b>Could something bad happen to me because I have taken part?</b> We don't think anything bad could happen. One or two children might feel upset about telling their story. If this happened to you, we would stop what we were doing and call for your parent, carer or nurse to make you feel better.</p> <p><b>What will happen to the story I've told?</b> We will listen and watch your recording. We will write out your story. We will then discover good ideas from your story, which can help us.</p> <p>The chaplain will come back to see you, or contact you by letter to know what we have found out about your ideas. We will then go away and read books to find out what other people think about spiritual need. All we have learnt will then be printed in a magazine, called a Journal. This means that many people can learn from you and take even better care of children, who stay in hospital. Remember no one will know that you said it.</p>
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**Appendix 2 (b)**  
**Consent Sheet**

<b>Spiritual Assessment Tools for Hospitalised School Aged Children</b>
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Please initial box

- |    |  |   |
|----|--|---|
| 1. | I confirm that I have read and understood the information sheet dated ( ) for the above study and have had the opportunity to ask questions                                  | <input style="width: 40px; height: 40px;" type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected | <input style="width: 40px; height: 40px;" type="checkbox"/> |
| 3. | I agree to take part in the above study  | <input style="width: 40px; height: 40px;" type="checkbox"/> |
| 4. | I agree that this study will be filmed and recorded  | <input style="width: 40px; height: 40px;" type="checkbox"/> |
| 5. | I agree that my home address can be used to make contact   | <input style="width: 40px; height: 40px;" type="checkbox"/> |

Name of patient	Date	Signature
-----------------	------	-----------

Contact Address: \_\_\_\_\_

Name of person taking consent (if different from researcher)	Date	Signature
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Witness	Date	Signature
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Version Number

1 for patient, 1 for researcher, 1 to be kept in hospital notes

## Spiritual Assessment Tools for Hospitalised School Aged Children

### PARENTAL QUESTIONNAIRE

Study Number:

The aim of this questionnaire will enable the researcher:-

1. to know if the child will understand the terms used in the study.
2. to correctly refer to the god/faith-figure of the child's culture/community.

#### QUESTIONS

1. Would your child understand what it means to feel strong inside?
2. Do they know what the word comfort means?
3. What is the term that is most commonly used in your culture/community to speak about a god or a faith figure?

## Appendix 2: Research Literature (d)



### Chaplaincy - Yorkhill Greater Glasgow and Clyde Health Board

Date

Dear (consultant's name),

#### **Clinician's Permission for Research Project**

I am coordinating a research project entitled, “**Spiritual Assessment Tools for hospitalised school aged children,**” that has received appropriate Ethical approval COREC 06/S0708/26 and Research & Development No. 06/CH10. Your clinical director is aware that I contact each consultant regarding this proposal.

The outline of the research proposal is below, and I have enclosed a reply slip indicating the course of action that you would like our researcher to take if your patients were to be involved. I would greatly appreciate if you could return the reply slip with the enclosed addressed envelope by the **9th February 2007**.

The research starts on 1<sup>st</sup> February 2007

#### **The Aim**

To investigate the insights gained through the use of spiritual assessment tool for hospitalised school children at Yorkhill.

#### **The Procedure**

A **sample of twenty school-aged children based in hospital**, would be asked to use a storyboard and sorting cards. The researcher will use pre-designed open-ended questions that will help the children to focus on the spiritual needs of the child. The story and cards will show the spiritual needs of the patient.

#### **The Researcher**

Rev. Alister Bull, Head of Chaplaincy Services

#### **What is involved at ward level?**

1. Consultant's preferred consent procedure (**see reply slip below**)

2. The researcher will need to introduce himself to the family, tell them about the project and give them the information sheets and return 24 hours later for consent.
3. If consent is attained the researcher will return to visit the parent for insight into their child's belief system by a simple parental questionnaire.
4. The researcher would meet with the child on their own and explain to the child that their help was needed to tell a story about a child in hospital.

## Appendix 2: Research Literature (d) (continued)

### What type of patient would be involved in the project?

1. In-patients
2. Children who have a command of the English language appropriate to their school age. This could exclude some special needs children and all children who do not speak English.
3. Children aged between 6 - 13 years old.
4. Children who are staying long enough for the consent procedure and a return visit by the researcher.

I have enclosed the patient and parental information leaflet, which provides more detailed information. However, if you require further details concerning the project please do not hesitate to contact me.

Thank you for your assistance on the matter. I look forward to hearing from you.

Sincerely,

Rev. Alister W. Bull  
Head of Chaplaincy Services

□-----

### Research Project Reply Slip

Spiritual Assessment Tools for hospitalized School-aged children

Clinician's Name: ..... Ward Area: .....

*Please circle your preferred option*

1. Are you agreed in principle that your patients may be used in this study?

Yes / No

2. If yes, how do you want the researcher to approach your patients/parents?

- a) Through the relevant ward nursing staff asking the patient/parent initially?

Yes/No

- b) Through direct communication with yourself - the patient's Consultant, each time?

Yes/No

## Appendix 2: Research Literature (e)



### Research Study Project

# Spiritual Assessment Tools for Hospitalised School Aged Children

#### **What is the research project?**

A hospital chaplain is conducting research on what spiritual needs of children in hospital can be discovered through using spiritual assessment tools suitable for children.

#### **What happens in the research?**

Your child is filmed and recorded telling a story using a picture board and sorting cards. The chaplain will ask questions that will help your child think about their spiritual needs through the story and sorting cards.

#### **Who can take part?**

1. Children aged 6 –13 years old
2. Children staying in hospital at the time of study
3. Children who can speak English as their first language
4. Children who can use a storyboard and sorting cards

#### **If you are interested in taking part please contact?**

Rev. Alister Bull,  
Chaplaincy Office,  
First Floor, Queen Mother's Hospital,  
Yorkhill,  
Dalnair Street, GLASGOW G3 8SJ  
Tel: 0141-201-0595  
Internal Ext: 80595  
Page No. 8064

e-mail: [alister.bull@yorkhill.scot.nhs.uk](mailto:alister.bull@yorkhill.scot.nhs.uk)

This research project has been reviewed by the Research Ethics Committee

### **Appendix 3: The Logistical Process for setting up an interview**

During a working day at the hospital I took the opportunity to recruit children for the project. I would take a research pack that contained the possible storyboards used, the sorting cards and information leaflets (see Appendix No.9), one for the child and one for the parent or guardian.

I would visit the ward areas and speak to a member of the nursing staff to explain my project and set out the criteria that was required for a child to be included in the research project. I then confirmed if I had received consent from the consultant to approach the family under his/her care. If I had not received the consultant's consent I would then find his/her secretary to seek consent in order to proceed.

Once consent by the consultant was verified I approached the family, avoiding any clinical procedural matters. I introduced myself, explained the purpose for my visit and then returned the following day to see if they had accepted and were ready to give their consent. If they were present and did not wish to proceed I offered them my assurances that this was not a problem. Whenever, they had accepted I would arrange a suitable time, often later on the same day. The consent forms would be signed by the parent and sometimes by the child, a witness signature by a nurse on behalf of the consultant. I would retain a copy, one would be left with the family and the other was inserted into the medical notes of the patient. A parental questionnaire would be discussed with the parent and/or child (see Appendix 2[c])) The following questions are asked.

4. Would your child understand what it means to feel strong inside?
5. Do they know what the word comfort means?
6. What is the term that is most commonly used in your culture/community to speak about a god or a faith figure?

For the child to be included in the project they would need to answer Yes for the first two questions. The third question depends upon their belief system or cultural context.

The majority of the interviews were conducted in a child's single cubicle room. This offered a discreet and convenient area for recording purposes that offered much more privacy. One interview was conducted at the bedside in a six bed bay area and two others were conducted in a ward sitting room with no one else present other than family.

When I returned at the arranged time with the filming equipment I set up a camcorder, tripod and a flatbed microphone. I recorded onto digital tape. I tested the equipment for sound level and visual quality. I sought to focus on the area where the sorting cards and storyboards would be located. The scope and the angle of the camcorder was aimed to avoid identifying the patient or any shiny reflection off the laminated board that would disguise the data from being decode at a later date. The interview was conducted and afterwards I thanked the family, packed up and returned the equipment and secured in a locked cupboard in my hospital office. The recruitment process would yield one or two recruits. There were three occasions I recorded two interviews in one day, all the other interviews were single events.

After the interview I copied the data from digital tape onto my laptop using software from Panasonic entitled Sweetmovie Life. I stored this data onto my NHS encrypted laptop purchased specifically for the research project. Each case was provided a number to anonymise the research recruit, from Nos.1 – 20.

I transcribed each interview onto other Qualitative research software called Nvivo<sup>327</sup> (Version 7 and 8). This took a period of two working days per interview. The interviews were coded to identify content. There was no formalised structure and the content was determined by what was mentioned by the children.

Once this was completed the process was repeated for each interview.

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<sup>327</sup> I attended a local seminar in Glasgow hosted by the company to be better equipped in its use. I had heard of this software through both my work context and the University faculty.

## **Appendix 4 – List of Technical Equipment for Research**

### **1. Laptop computer**

- a. A laptop computer – DELL Latitude D620 was purchased through the NHS IT service Department
  - i. This meant that the laptop was encrypted and met the ethical standards for the protection of Data
  - ii. The performance and function of the laptop would also be serviced by the IT service Department
    1. Installation of SweetMovie Life
    2. Nvivo
  - iii. This was also compatible with the NHS server and so I was able to back up information from the laptop to the server
- b. Extra memory purchased to maintain performance
  - i. Memory capacity was doubled in order to cope with the volume of data building up through video.

### **2. Panasonic Camcorder**

- a. This was researched by the Medical Illustrations as the most suitable model for my research purposes
  - b. Contained within this equipment was software called Sweetmovie life that enabled me to transfer the data from the digital tape to the laptop
    - i. This enabled me to use the one laptop to access the interview and code and transcribe.
3. Tripod
  4. Digital tape

The funding of the equipment was made possible by a research grant supplied by the College of Healthcare Chaplains Research Group.

## **Appendix 5: Summary Data of Interviews**

## **Appendix 6 – Case Study Summaries**

### **Introduction**

The purpose of these summaries is to provide the reader with sufficient contextual information to recall a Child's profile when reading data drawn from their interview and is referred to during the thesis. There are no dates, names or places in the profiles below that would enable the reader to identify a child. The profiles are written to be stand alone profiles so they can be used for reference purposes. Therefore, there are common features that if read sequentially would be repetitive.

### **Stage 1**

#### **Case 1**

An 8 year old boy who was admitted for a renal condition. He had been admitted before to the hospital. He played with the space game followed by the sorting cards and his mother was present through the interview. It was difficult to assess the nature of the interview as this was the first case. However, I did feel that the child found it hard to focus and had a more frivolous attitude towards play that was hard to control. However, he enjoyed the experience. He did experience discomfort during the interview. The interview was stopped for him to go to the toilet. When we resumed the dynamics were different as he was more subdued.

#### **Case 2**

A 13 year old girl who was admitted for asthma. She had a chronic condition that required repetitive admissions. She played the shopping trip followed by the sorting cards. Her mother and younger brother were present and was conducted at the bed side in a 6 bed bay area. She was friendly and willing and was the only participant who volunteered that they did not have a religious faith.

#### **Case 3**

A 10 year old girl who had been admitted to hospital and was waiting for news if her symptoms were diagnosed with Crohn's disease. She played with the shopping trip followed

by the sorting cards. Her mother was present. The interview was conducted in a cubicle. She was very quiet during the interview. I found the recurring replies, “I don’t know” difficult to know how to address during the interview.

#### **Case 4**

An 8 year old boy who had been admitted to hospital for appendicitis. He played the space game followed by the sorting cards. He was a quiet natured boy but who was still responsive. His mother was present. She shared her opinion that there should be more opportunity to discuss religion but her son had indicated that that this was not a topic of interest that he wished to develop. The interview was conducted in a cubicle.

#### **Case 5**

A 7 year old boy who had received very serious cardiac surgery and was in a time of recovery. He played the space game and sorting cards. His step father was present during the interview. This was one of the latest interviews conducted in terms of time of day. The boy was a lively personality and displayed a considerable amount of energy in his participation despite his condition. The interview was conducted in a cubicle.

### **Stage 2**

#### **Case 6**

A 10 year old girl who had been admitted to hospital for asthma. She had been regular to hospital for this condition. She played with the sorting cards first followed by the shopping trip game. She was the first child in what has been referred to as Stage 2 the development of the SAT portfolio. I felt the interview flowed. Her mother was present but did not participate. The interview was conducted on the day of her discharge. She was a quiet but confident girl. She shared through the interview that there were relational challenges at school and demonstrated a clear coping strategy to deal with it.

#### **Case 7**

A 6 year old girl who had been admitted for treatment for cystic fibrosis. She had been regular to hospital for this condition. She was one of the youngest recruits. She used the sorting cards and was the only child in Stage 2 to select the Museum Trip storyboard. Her

mother was present. She enjoyed the interview and engaged with the process in a positive way. However, it was difficult to appreciate if the child understood the purpose of the exercise as the mother assisted her daughter on a number of occasions during the interview. There was an interruption by a staff member to monitor her medication. The interview was conducted in a cubicle.

### **Case 8**

An 8 year old girl who had been admitted for an extensive orthopaedic procedure that was a series of interventions. She was very familiar with the hospital environment at the point of the interview. Her main carer was her grandmother. There were social issues for this arrangement. She used the sorting cards and the shopping trip storyboard and there was no guardian present. She engaged well with the interview conducted in a cubicle and was very talkative. I felt that she covered many topics in an unfocused manner but was not prepared to explore more fully areas of her social background. She was the second longest interview.

### **Case 9**

A 9 year old girl who was in hospital to have a colonoscopy. There was no parent/guardian present during the interview. She used the sorting card game and the shopping trip. She engaged in a quiet but still chatty demeanour. There was an interruption by a member of staff who was checking on medication. The interview took place in a cubicle.

### **Case 10**

A 9 year old boy who was admitted to hospital for e-coli. The interview took place during his time of recovery. His father was present during the interview. He played with the sorting cards and had selected the football trip storyboard. He quietly progressed through the interview and engaged well with the process. There was an interruption near the beginning of the interview by a member of staff.

### **Case 11**

A 13 year old boy who had Crohn's disease and was very familiar with the hospital. The interview was conducted at a very advanced stage in his treatment for his condition where there was a more settled approach and so could anticipate the nature of his treatment. He played with the sorting cards and selected the football trip story. He engaged positively and confidently with the SAT. There was no parent present but was conscious of the support of

his family. At the point of the interview he volunteered information that he was a practicing Christian. The interview was conducted in the “youth room” on the ward.

### **Case 12**

A 10 year old boy admitted into an orthopaedic ward because he had been knocked down by a vehicle. He played with the sorting cards and selected the football trip storyboard. There was no parent/guardian present. He presented himself as tough and “street-wise” throughout the interview. He engaged well in the interview and was confident. He had been unconscious on admission but had obviously discussed at length what had happened to him. He was disenchanted with education but had a strong sense of loyalty to his family. The interview was conducted in a cubicle.

### **Case 13**

A 13 year old girl who was admitted to hospital for ongoing treatment for cystic fibrosis. Hospital was a familiar environment. She played the sorting cards and selected the football trip. There was no parent/guardian present. She was a talkative and sprightly girl who engaged with the interview in an enthusiastic way. It was the longest interview. She was a fun loving girl who loved contact with friends. The interview was conducted in a cubicle.

### **Case 14**

A 13 year old boy who was admitted to hospital for treatment of cancer. The interview was conducted well after his diagnosis and was during one of his planned treatments when he was admitted as an inpatient. He played with the sorting cards and selected the shopping trip. He is the only male to select this storyboard. He was a confident and polite boy who engaged with the interview with a serious commitment and positive manner. A recurring theme of his interview was the emphasis on his friends. There was no parent/guardian present. The interview was conducted in a cubicle. There were two interruptions by a member of staff checking medication near the end of the interview

### **Case 15**

An 11 year old girl who was admitted to hospital for continued extensive orthopaedic procedures to her leg. This involved a metallic leg brace. The interview was during this time of recovery. She was familiar with the hospital environment. She played with the sorting cards and selected the shopping trip. This was one of the longer interviews. While she

engaged positively and was very talkative, she was hesitant to explore social issues concerning her background. There was no parent/guardian present. The interview was conducted in a cubicle.

### **Case 16**

A 12 year old girl who was recovering from a broken leg after being knocked down by a vehicle. The interview was conducted during her time of recover when her leg was suspended in traction. This requires several weeks of confinement to the hospital bed. She was the oldest to have her parent/guardian present. The parent did not participate. The interview was conducted in a cubicle. There were two interruptions by a member of staff. She engaged positively with the interview but required encouragement but there were moments I was unsure of the manner of this child who sought to impress or make a point.

### **Final Stage**

#### **Case 17**

A 10 year old boy who was in for ongoing treatment for cystic fibrosis. was very familiar with the hospital environment at the point of the interview. He used the Apple Tree exercise and the hospital storyboard. This was the format for all children in Stage 3. The parent/guardian was present for the latter part of the interview and made a personal contribution at the end but not during it. The child was gentle nature but quietly confident and aware of his supportive family. He engaged with the SAT in a positive manner and when uncertain of a procedure would ask for clarification. The interview was conducted in a cubicle. This child was used for the Case Study in Chapter 9.

#### **Case 18**

A 7 year old girl admitted for a renal condition. This was continued treatment after a hospital stay while they were abroad on holiday. The interview was during her treatment and recovery. She was positive, bright and engaging and was forthcoming with information. There was a parent/guardian present. The interview was conducted in a cubicle.

**Case 19**

A 7 year old girl who was receiving ongoing treatment for cystic fibrosis. She engaged well in the interview and was chatting freely about information. There was no parent/guardian present. The interview was conducted in a cubicle.

**Case 20**

A ?? year old girl who was admitted to the orthopaedic ward due to breaking her leg. It was put in traction and was confined to a hospital bed for several weeks. She was sociable and engaged at her level with the process. I discovered subsequently that while she is part of mainstream education but requires learning support. She socially interacts with her own age and is able to engage in intelligible conversation. This interview was different to others as it was not until during the discussion that I felt she had cognitive limitations and concentration. There was no parent/guardian present. The interview was conducted in a cubicle.

## **Appendix 7: Child Development Table comparing theories**

## **Appendix 8: Thesis outline at December 2010**

## Appendix 9

## Appendix 10