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**Experiences of developing cancer and palliative care services in one
community in North West England 1976-2000: An oral history and
documentary reconstruction**

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Submitted in fulfilment of the requirements for the degree of PhD

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Abstract

The purpose of this study was to explore how cancer and palliative care services developed in one place and changed in the course of time. Research on how local cancer and palliative care services have developed is limited. A small number of researchers have provided accounts of hospice developments nationally, but they did not explore individual experiences and the micro context in detail. Other studies have examined accounts of developing local cancer support services, but not hospice developments. This research addresses the question - how were cancer and palliative care services developed in Lancaster 1976 – 2000? Oral history and documentary sources were used to generate data, which was analysed using thematic analysis/constant comparison. Social constructionism offered a fruitful theoretical basis that increased understandings of oral history accounts. A snowball sample recruited a broad group of participants that had been involved with the local cancer and palliative care services in the relevant period. Thirty five interviews were conducted.

The study revealed that services developed in the absence of national planning; participants worked to make them respectable, but there was tension at times. Progress was shaped by a combination of individual and social factors. Services evolved outside the National Health Service, yet alongside oncology and were therefore *tripartite* in character. Elsewhere developments were often fragmented. Many participants were involved in all the local services; they created networks and collaborated to form comprehensive facilities, which were available from diagnosis to the terminal stage of illness. The approaches complemented each other to reveal that at the macro level services were initially flexible. In time they became more structured, as social, historical, economic, professional and political mechanisms in the broader context impacted to shape them; this created some challenges. The study also uncovered aspects of the meaning of compassion. It revealed that compassionate practices challenged the rationality of conventional approaches and shared relativist perspectives because participants found different ways of providing care. All of these findings contributed to new knowledge about the development of local cancer and palliative care services. The study was limited by the historical period, perhaps by the place and because the reconstruction was one interpretation. It is possible there are others.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

A solid black rectangular box redacting the author's signature.

Printed name: Sara Jane Denver

Introduction

This thesis reports the method and findings of a research study that explored how cancer and palliative care services developed in one community. The purpose of this introduction is to describe the background to the study, which I carried out to address the research question: ‘How were cancer and palliative care services developed in Lancaster 1976-2000?’ This introduction explains the research problem and reason for carrying out the study. It also states the research aims and illustrates the broad and dynamic questions/topics that were used to guide the oral history interviews. The final part of the introduction concludes with a summary of the structure and purpose of each chapter.

Research problem

There is little understanding of how cancer and palliative care services have developed in local settings, yet it is important to recognize the contribution that local facilities have made to their communities in the course of time (Overy and Tansey, 2012). During recent years a small number of researchers have explored national hospice developments at the macro level, but this work did not include cancer support organisations, nor did it examine individual experiences of developing local services in detail (Clark et al., 2005). Consequently, research into how cancer and palliative care services evolved in the local setting is largely unexplored. Furthermore in 1976, the beginning of the period of my study, there were no long term plans for cancer or palliative care services. Concerns were raised that facilities elsewhere were fragmented because they had evolved in a haphazard way. For example, some resources emerged within the National Health Service but others developed as independent charities; gradually policy frameworks began to emerge (Department of Health, 1995; Department of Health, 2000; Higginson, 1993; Report of a Working Group of The Association of Cancer Physicians, 1987 (see McIlmurray, 1987); Report of the Working Group on Terminal Care, 1980). Yet, until this thesis no detailed research had been done to examine the impact of this

history on the development of local cancer and palliative care services in one setting. The reason for carrying out this work in Lancaster was that anecdotal evidence suggested cancer and palliative care services there were unusual because they had developed *comprehensively* (McIllmurray, Gorst, Holdcroft, 1986). By this was meant that they had evolved alongside oncology. My interest in the field stemmed from close personal losses and experiences when I was a nurse (in oncology) and later as a solicitor. These earlier encounters gave me a greater understanding of the importance of good quality palliative care and highlighted that end of life care is a matter of concern for everyone because it will impact on us all at some point. Furthermore, the population is living longer so more people will require high quality care at the end of their lives (Wilde, 2008). In addition, when I studied for the Postgraduate Certificate in Health Research (End of Life Care) at Lancaster University, I explored the national and international history of hospices and palliative care. This made me reflect on the similarities between my oncology experiences and the approach taken by those in hospice care - the focus was not just on physical issues but included emotional factors (McIllmurray, Gorst, Holdcroft, 1986). It also indicated that there was a gap in the knowledge base regarding local developments. All of these considerations led me to form a view that research into how cancer and palliative care services developed in the local setting would make a very interesting analysis for my PhD thesis.

Aims of the study

This study will show how individuals developed cancer and palliative care services in one community from 1976 to 2000. It will increase understandings of how facilities evolved and how needs changed over time (Grande et al., 2009). In addition, the study will explain where my research fits with the work of others; it will indicate where it takes matters further and therefore makes a contribution. Furthermore, it will reveal the gaps that remain open for future research, explain the limits of my study and describe what worked well and what did not. It will also report some unexpected findings. The specific aims of the research were:

1. To ascertain how individuals developed cancer and palliative care services in one community.
2. To capture experiences of how care was provided at the end of life.
3. To place the research findings about service development in the wider context of cancer and palliative care issues.
4. To increase understandings about the development of cancer and end of life care provision over time.

It was through addressing these aims that the study was able to answer the overarching research question.

Research questions

The key purpose of this research was to generate knowledge about the development of local cancer and palliative care services, in order to increase understandings as to how they evolved and changed over time. At the beginning of the time period of my study there was no strategy for cancer or palliative care services, however by the end point national policy had evolved to a significant degree (Department of Health, 1995; Department of Health, 2000). In the absence of any long term planning it was down to those at the grass roots to develop local policy, yet what were the implications of this on the participants and the services as they developed? What kind of services evolved? What impact did social, political and professional mechanisms in the wider context have on the shape of these services in the course of time? The key broad topics/questions that guided my study were:

- How did individuals come to be involved in cancer/palliative care?
- What was the philosophy of care?
- Did participants feel part of something special and unique?

- How was pain managed - with drugs, spiritual care and complementary therapy?
- What links and bonds were forged between/across organizations?
- Paths not taken.
- Charismatic leaders.
- Routinization and bureaucracy.
- Research and education.
- Changes and challenges.

Study method in outline

I conducted a qualitative study using oral history combined with documentary sources to reconstruct the story of how cancer and palliative care services developed in one place during the relevant period. Accounts from oral history data were analysed and interpreted through a process of constant comparison, which has its roots in grounded theory and has been used successfully in a number of cancer and palliative care studies (Bowman and Singer, 2001; Chapple, Ziebland and McPherson, 2006; Glaser and Strauss, 1967; Seymour et al., 2003; Seymour et al., 2004; Steihauser, 2001; Terry et al., 2006; Thomas, 2005). By focusing on individual experiences in oral history accounts it was possible to link these with wider social, individual, historical, economic, and political factors to demonstrate that they impacted on the development of local cancer and palliative care services (Mallinson et al., 2003). The thesis also shows that social constructionism offered a theory for understanding more about some of the oral history accounts because of shared epistemological constructs. For example, oral history and social constructionism question rationality, search for differing ways/viewpoints and are democratic/non-judgmental (Pinch and Bijker, 1984; Thompson, 1988). The method and methodology complemented each other to reveal that local facilities did not develop in a vacuum; there were broader contextual factors such as social, historical, political and

professional mechanisms that operated to shape services and change them over time. The methodology and method worked together to reveal that at the macro level services were initially flexible and became more structured in the course of time, as a result of these broader mechanisms; it also revealed that there was tension at times. Similarly, at the micro level the method and methodology complemented each other to reveal meanings about compassion, and how compassionate care was provided to those with cancer and palliative care needs. The next section describes how the thesis is organized.

Structure and contents of the thesis

Chapter 1 comprises a broadly based review of the literature and key changes in relation to cancer and palliative care services, in order to set the scene on the state of facilities during the relevant period (1976-2000). I explore social, historical, professional and political factors that operated to shape cancer and palliative care services in the wider arena, as services began to emerge in Lancaster. I also review the role of professional bodies, examine key reports that surfaced at this time and discuss some of the challenges that arose in relation to the direction services were taking.

In **Chapter 2** I deal with methodology, I explore the problem of a conventional materialist focus for research methodology and method in cancer and palliative care work. I examine some of the challenges that were launched and explore how difficulties were resolved. I demonstrate that social constructionism could increase understandings of oral history accounts because of shared epistemological factors and these are also explored.

Chapter 3 describes the method, study design and analysis. I report how I used oral history and documentary sources to begin to address the aims of the study and answer the overarching research question. I describe and justify the design by drawing together the methodology described in chapter 2 with the method to show that they complemented each other because of

shared epistemological factors, and that the methodology provided a framework for understanding more about the oral history accounts I collected. I explore the advantages and challenges of using oral history and documentary sources. I introduce the study site, the participants and describe the recruitment process. In addition I indicate how questions were created and the method used for data generation, analysis and interpretation.

Chapter 4 is the first of the empirical chapters, it explores the ‘microclimate’ of local cancer and palliative care service development, and provides an overarching picture of how a local *tripartite* cancer and palliative care service evolved and changed in the course of time. By focusing on the accounts of participants and combining these with documentary sources, it was possible to construct a view of services developing from ‘scratch’ to ‘routine’. Furthermore the chapter addresses some of the aims of my study such as how individuals developed cancer and palliative care services locally. It begins to place findings in the wider context of cancer and palliative care issues, and increases understandings of cancer and palliative care provision over time (see aims 1, 3 and 4).

In **Chapter 5** I explore the philosophy of care and practice of those involved in the local provision of cancer and palliative care services, revealing that it differed to conventional approaches. In addition, I use some elements of social constructionism to increase understandings of oral history accounts about compassion – what compassion meant and how compassionate care was provided. I address some further aims (1 and 2) of the study by capturing experiences of how care was provided at the end of life, and I ascertain more about how cancer and palliative care services developed in one place.

Chapter 6 examines some of the challenges and how they impacted on the development of *tripartite* services. I describe the historical hierarchical context in which services developed and its impact on participant’s experiences. I uncover key social and individual factors that operated to address the challenges (charisma and networks), as well as broader mechanisms

that shaped the cancer and palliative care services. Consequently, this chapter builds on the knowledge generated in the preceding empirical chapters to uncover more information about how local cancer and palliative care services developed. It also places the research findings in the wider context of cancer and palliative care issues, to increase our understanding on the development of cancer and end of life provision in the course of time, and thus helps to address some key aims of my study.

In **Chapter 7** I conclude by drawing out the significance of the key findings and conclusions interpreted in my study for our understanding of the development of local cancer and palliative care services, to show that the thesis has made a contribution to knowledge. I indicate that the methodology and method complemented each other to reveal how these services developed at the macro and micro levels. The chapter confirms the extent to which the aims of the study were achieved by drawing on the outcomes of subsequent chapters. I link these findings to broader cancer and palliative care issues from my literature review. I consider the learning from this thesis and explain how I have added to the field, by mentioning connections with and distinctions from the published work of others. I describe the impact of social, historical, professional and political mechanisms on local developments. I consider what worked successfully/what did not, and I discuss the limits of the work. I also reflect on what questions have been answered, gaps that exist and what future studies might flow from my research. I summarize the key findings and conclude the chapter, and the thesis, with conclusions and observations on the development of these facilities during the relevant period.

I move on now to the first chapter, which reviews the literature.

CHAPTER 1

THE NATIONAL CANCER AND PALLIATIVE CARE LANDSCAPE

1.1 Introduction

The main purpose of my study was to analyse how cancer and palliative care services developed in Lancaster from 1976 to 2000. This chapter sets the scene on the status of cancer and palliative care services in the United Kingdom over the same period. Its aim is to provide context for the historical analysis of cancer/palliative care services in Lancaster, and to facilitate an examination of the similarities and differences between local and national achievements. Furthermore, it also enabled me to interpret the impact of wider social, professional and political mechanisms on the shape of local cancer and palliative care developments (see chapters 4-7). Despite its importance cancer and palliative care services have emerged in the absence of an overarching plan, and there is little research on the history of these services. From a virtual absence of facilities in the 1950s the service has grown to be not only a national priority, but has also seen the development of professionals both in terms of medicine, nursing and other allied disciplines. The little historical work that there has been provides a national overview of the development of hospices and palliative care, but research that explores local developments of cancer and palliative care services in detail is limited.

This chapter identifies the main areas that have been covered by researchers on the history of services; reviews the role of professional bodies and examines the key reports that were in circulation by 2000. It explores the challenges that arose and uncovers different views that were emerging about the way the services were evolving. This broad literature review increased my understanding of the field and helped frame some of the research questions (see 1.4)¹. It also enabled me to link my work to that of others, critique the literature and define the gap that I have mentioned. Murray (2011) argues that review writers also have to say what they are not going to write about and why. I left out work about the history of traditional hospices that pre dated the modern hospice movement because I needed to provide a birds-eye

view of the status of services from 1976 to 2000. Similarly research on the history of Cicely Saunders, hospice pioneer has not been included because most of the sources had already been interpreted; therefore it would have been difficult to construct a history that moved beyond description. Although I have of course referred to Cicely Saunders' work here and also where it relates to accounts about practices in the empirical chapters (see chapters 4-6). I will now explore these developments in some detail.

1.2 Status of palliative care services

In this section I analyse the state of hospice and palliative care services between 1976 and 2000 to reveal the professional, political, social and economic developments that were taking place in the United Kingdom. There were four key themes: early developments, hospice and wider factors, generating interest and greater cohesiveness, which are described in detail.

Early developments

There has been a small but significant number of studies that have evaluated and reconstructed the history of support services and hospice care, in particular the work of David Clark. These studies were important because they began to uncover how facilities developed and opened up a previously neglected history for further exploration (Clark, 1990; Clark, 1991; Clark, 1992a; Clark, 1992b; Clark and Neale, 1994; Ingleton et al., 1995; Ingleton, White and Clark, 1996). Clark's research has increased understandings of hospice/palliative care issues, and revealed the impact of prevailing social, economic and cultural factors on hospice evolution. For example, he found that services often developed as a result of community projects funded by charitable sources, and much of the progress occurred during a relatively short period. This literature shows how in the 1980s there was an intense period of hospice development and a large proliferation of centres in the United Kingdom. However, this was mostly sporadic and there was no national planning for cancer, hospice or palliative care. Although the National

Health Service aimed to provide free and equitable health care to the population (in accordance with the National Health Service Act, 1946), it did not have a strategy for cancer or palliative care services (Boyle, 2011). Therefore, some cancer and palliative care facilities emerged within the National Health Service; these will be explored later in this chapter but most evolved outside the statutory framework. This raises some interesting questions as to why most hospices develop outside the mainstream, and what kind of relationship existed between the State and voluntary endeavour. Clark and Neale (1994) used two case studies to explore the development of community based hospice approaches at High Peak Hospice, Derbyshire and Newark and District Hospice Aid, Nottinghamshire (both areas already had inpatient hospices). The researchers looked at their integration with existing networks and relationships with funding bodies. There was some tension between these independent projects and their respective District Health Authorities. In Newark this was because lay members of the group tended to see day care as an interim service, which would lead eventually to a 'proper' hospice with inpatient beds. At High Peak the plan was to provide social care in the community rather than medical or nursing care, but the District Health Authority would not fund this idea. Furthermore, there was some tension in both places between community groups such as District Nurses and General Practitioners and the community hospices. The key reason for this was that a new community-based service '...is not intended to usurp statutory provision, but by definition points to some inadequacies within it' (Clark and Neale, 1994, p.208). However educational activities such as seminars and meetings helped to create worthwhile links between the groups and improve relations.

One oral history source on the history of palliative medicine was the Witness Seminar (organized by the History of Modern Biomedicine Research Group at Queen Mary, University of London) where expert's discussions were recorded and transcribed (Overy and Tansey, 2012). These provided a different kind of history to that of an oral history interview through the 'voices' of experts in discussion with each other. Therefore there was an opportunity to find information not recorded elsewhere. For example, palliative medicine consultant Andrew Hoy revealed that when he was a medical student there was always a clear vision that St Christopher's Hospice would remain outside the National Health Service. In his view this was because it could not be associated with the dissatisfaction brought on by the medical neglect of

the dying within that organization (Overy and Tansey, 2012). Another possible reason for staying outside the statutory services was because this ensured a degree of independence, which was not found elsewhere. This appealed to some individuals; in addition it was also a morally acceptable alternative to private medicine for those who did not wish to work in the National Health Service (Small, 2000). Saunders (2000) argued that the main reason for hospices developing outside the Health Service was because the medical profession was not willing to engage as palliative care was not seen as important work. A key reason identified as to why this was problematic was that conventionally medicine was socially powerful and hospice was weak. Yet the burden of justifying the palliative care approach rested heaviest on those in the marginal group who were working in palliative care (which was similar to the findings of Nicolson and McLaughlin, 1988 in work on multiple sclerosis).

In the early days palliative care was afforded little priority and consequently there was generally no financial support to enable palliative care to develop as part of the statutory services. During the time frame covered by my research, the responsibility for public funded health care in England and Wales rested with the Secretary of State for Health supported by the Department of Health. The Department operated at regional level through Regional Health Authorities; the duty for commissioning health services at local level was with Area Health Authorities. Subsequently, they were replaced with 192 District Health Authorities following the Health Service Act, 1980 (these were eventually superseded by Primary Care Trusts in 2000) (Walshe et al., 2004). During the 1980s the Government introduced cost-improvement programmes, performance indicators and 'general management' into Health Authorities and hospital units because it perceived these changes would improve efficiency. Yet as Boyle (2011) argues, in spite of these measures financial pressures on the National Health Service continued throughout the 1980s.

There were then further changes to the structure of facilities because the National Health Service and Community Care Act (1990) introduced the 'internal market' and competitive tendering for services. On a practical level the changes of 1990 meant that the commissioning and delivery of services were now separated. District Health Authorities were established as

'purchasers' of health services rather than providers, they became responsible for entering into contracts to buy services to meet the needs of patients. General Practitioner fund holders provided General Practices with the option of taking responsibility for the purchase of limited services for patients, as well as providing primary care services, all within cash limited budgets. On the provider side hospitals and community health services were established as semi-independent non-profit-making National Health Service Trusts. Contracts were established between purchasers and providers. Providers were encouraged to compete in respect of price and quality because it was seen as a way of increasing efficiency. It suggests that an 'independent' approach to the provision of health services generally was encouraged by the rational political perspective at the time. Furthermore, as there was no overarching plan for cancer or palliative care services, this might have had an impact on whether services were inside or outside the National Health Service (Marie Curie, 1988 cited by James and Field, 1992).

Consequently, voluntary organizations like hospices also became 'providers' of health care though they were generally outside State control. The National Council of Voluntary Organizations (2013) argues that such charities were important in shaping ideologies, values and institutional structures. Charities often worked with the poorest and marginalized in society like the dying but they did not have any significant input into national strategy. This was because conventionally those involved in hospices did not play a central role in planning the National Health Service facilities. Two key innovations were identified that ensured charities played a greater role. First, Help the Hospices and the National Council of Voluntary Organizations both worked to influence policy and ensure hospice care was integral to developments (Help the Hospices, 2013). Second, the Government through the Department of Health issued an agreement between voluntary bodies and the National Health Service enabling charities to have a central part (this came in 2004, outside the period of my work) (Boyle, 2011). Nonetheless, the independence between voluntary and state services meant that generally facilities were not comprehensive; they had developed arbitrarily and resources were available in some places but not in others. For example, there was a growing awareness of the psychological consequences of having cancer, yet many regions did not provide any psychological supportive care (McIllmurray and Holdcroft, 1993).

During the time frame of this study there were two main reasons detected as to why relationships between the voluntary and statutory bodies were much more fluid and not always cohesive. First, most hospices were not part of the National Health Service therefore they were not subject to the same structured requirements. Physician Robert Twycross argues that it was often through ‘informal’ links with key figures like Cicely Saunders that many pioneers originally become involved in this field (Overy and Tansey, 2012). Similarly, people often decided to engage in this work through personal connections and social networks. This could have been because decisions were often made in networks rather than through more formal procedures (Small, 2003). Many of the individuals in hospices worked flexibly, for example in relation to recruitment of staff/volunteers, which suggests that the services and funding arrangements were not subject to the same policy requirements as State facilities would have been. This also meant that independent services did not fit neatly into the ‘same’ strategy as State services. One example of this could be found in the *modus operandi* in relation to referrals; in many places Cancer Support Nurses referred individuals to hospices and in some areas patients could self refer (Help the Hospices, 2013; Youren, 2007). In many places individuals with cancer could also refer themselves for care as was the case with Tak Tent, a voluntary organization set up in Glasgow to provide support to people affected by cancer (McArdle et al., 1996) (see later in this chapter). Yet in the National Health Service General Practitioners were the ‘gate keepers’ and referred individuals for all other services (except for Accident and Emergency care and Genito-Urinary Medicine).

Second, some voluntary and State services worked cohesively, but others did not because of different perspectives about whether services should be structured or flexible and there was no overarching guidance. Although there was a need to plan, to have priorities and a vision about how one might go about achieving them, this did not appear in the strategy until 1997 when it was echoed in the Department of Health White Paper ‘The New NHS: Modern, Dependable’ (Small, 2003).

In short, two key factors pointed to why there was such inequitable provision of resources. The first stemmed from the absence of strategy described and the second from a lack of

financial commitment. Sometimes financial support was available from the State for voluntary-sector palliative care services, but this varied between areas so provision was not systematic (Boyle, 2011). I found a further justification for this line of argument in the history of St Columba's Hospital, a voluntary hospital for terminally ill cancer patients. The Kensington, Chelsea and Westminster Area Health Authority attempted to close it in 1979 to save £200,000 per year and realize capital on the sale of the site (Murphy, 1990). There were broader socio-economic structures operating on the shape of terminal care because the National Union of Public Employees became involved in an attempt to save the hospital. Nonetheless, dying patients were transferred and services ceased when the hospital was eventually sold to a private purchaser. It is interesting to reflect on this history because it uncovered unexpected problems arising from a relationship that had not been planned or integrated historically. For those delivering services there were tensions between a responsibility to promote the health of the population, a utilitarian view that sees a need to put an overall population benefit first, with the long-standing Hippocratic approach of putting the individual patient's needs first and foremost (Small, 2003).

Other voices were anxious about the development of strategy and the issue of 'independence', some charities pointed out that they could make decisions that were impartial because they did not have to take politics into account (National Council for Voluntary Organizations, 2013). There were concerns that once an organization was in receipt of state funding there would be an erosion of autonomy, which could go some way to explaining why there was not closer integration in the early days. Proponents of the hospices were able to taper the focus of their work and develop highly specialized skills because they were independent, flexible and focused their care on people with cancer; such specialized practices were seen as part of the success of the modern hospice movement (James and Field, 1992).

Hospice evolution and wider factors

Small (2000) conducted oral history work on the development of hospices in the United Kingdom, which was part of a larger piece of research that began in 1995 at Sheffield University ('Hospice History Project', 1995). Accounts were analysed thematically to see how pioneers impacted on developments. They were also considered in the light of wider social and cultural mechanisms to see how they shaped services. The study explored national evolution with key activists in the hospice movement, it had the capacity to add to what was already known and expand knowledge of developments. This work was important for four key reasons. First, it acknowledged that hospices were having an impact on care outside the hospice building. For example, some of those involved in hospices took their ideas/skills to provide care to those with a range of medical conditions in other places. Second, hospices started to provide education to enable others to improve their skills so that they could be applied in settings beyond the hospice. Third, those working in hospices shaped the debate about the social, psychological and spiritual context of death and dying. In the course of time there were moves to provide care at an earlier stage rather than exclusively at the end of life (Higginson et al., 2006; Woods, Webb and Clark, 2001). Fourth, Small (2000) also critiqued practices that separated care at the end of life from other forms of statutory funded care. Questions were raised about providing special care in one place to those dying from cancer when they were in the minority (Murtagh, Preston and Higginson, 2004).

The aim of my study was not to contest this view; rather it was the intention to reveal similarities and differences. In addition, it aimed to build on the oral history work that had been done and take it further by including the development of cancer and palliative care services in the local rather than national setting. Furthermore, this research resonated with a similar methodology to that underpinning the Hospice History Project (1995) because it sought to develop a wide-ranging, thematic approach to interviewing many people involved in cancer and palliative care (see chapters 2 and 3).

The publication of *'A Bit of Heaven For The Few?'* was the product of ten years of interviews and research which emanated from the Hospice History Project (Clark et al., 2005). This research interpreted an oral history about the development of the modern hospice movement in the United Kingdom, constructed at a particular time. It explored and contextualized the development of hospice and palliative care by drawing on interviews with professionals/volunteers, and exploring themes reconstructed from transcripts (Clark et al., 2005) (see chapter 3). The researchers used thematic analysis to reconstruct history rather than to explore how the work resonated with a particular epistemology, or could be interpreted to include a methodological explanation for developments. Clark et al (2005) presented a different image to that which existed in documents produced by individual hospice organizations, because they examined history from the experiences of participants in the context of their lives. The participants were invited to talk freely so that the researchers could ask the 'what, why and how' types of questions; this was important because it enabled significant issues to be explored. In addition to uncovering factual information it discovered motivations for actions and reflections on events.

It was possible to contextualize the accounts to show what was happening at specific points in time in society, the professions, and the participant's lives. It sought the 'big picture', the shape of their work in their lives, as well as personal assessments of the influence of their work on the lives of others. It uncovered that involvements in the hospice world had been something of special significance; many of the achievements arose as a result of charismatic individuals coming together in a community. In addition personal motivation, particularly the desire to do something to make things better was a strong motivational factor that led pioneers to this work. Social connections and the ability to network shaped hospice developments because they generated support and funds for projects that were outside the National Health Service. Other findings pointed to the importance of multidisciplinary teamwork, the ability to work together in a variety of ways for a common purpose despite elements of tension. Conventionally professionals made the decisions about treatment plans and care, but now there was a change in attitudes because the multidisciplinary team provided patients with more information about their condition and encouraged them to become involved in decisions. It was significant because individuals were now consulted about preferences and families were

included in a way that was previously unknown. Furthermore, this work also suggests the approach contributed to a change in the way illness and dying were conceptualized. There was a move away from customary practices that focused on the mechanics, or physical aspects of disease to encompass social, emotional and spiritual elements (see chapter 2). For example, Cicely Saunders explained how she created the concept of 'total pain' because she developed a level of intimacy with patients and had an ability to listen, so care could be tailored to address the needs of the whole person (see also Saunders, 1996). Within a decade of St Christopher's opening (in 1967) it was accepted that the principles of hospice care could be practised in the National Health Service hospitals, day care and home care facilities.

Three key messages emanated from *'A Bit of Heaven For The Few'*. First, it advocated that palliative care should be made available to everyone by integrating it in the wider system. Second, it supported inclusive care thereby making palliative care available regardless of diagnosis and disease trajectory. Third, it promoted the extension of palliative care to all areas where care takes place regardless of social situation or means. For example, this would include National Health Service hospitals, hospices, community services, home care, prisons and nursing homes. The method used by the Clark et al (2005) study needs some qualification. Although participants were encouraged to talk freely the interviews were done 'on the record'. It is possible that this could have restricted what was revealed, participants might have had a greater variety of stories to tell had they been anonymous (Dore, 2012). On the other hand such an approach would not have credited individuals for their contributions, and there is a line of argument that people should be recognized for the stories they give and the contributions they make (Oral History Society, 2009). These were 'elite' oral histories and began with Cicely Saunders' interview. The interviewees were asked to nominate others who might contribute to the project, and thereafter participants were invited to name other potential candidates hence a 'snowballing' or 'reputational' method. Relying on recommendations from leaders in the field might have recruited those more likely to have positive viewpoints because they championed the hospice movement. Most participants were senior, well-known, influential figures that as experts were certainly less open to challenge, and could have had a message to portray that promoted their work (Berry, 2002). Furthermore, some participants might have reflected more on good experiences because they had retired and were no longer

active in the field. Others involved in hospices at the time possibly felt under pressure to be more cautious because they needed to justify actions.

Overall the work by Clark et al (2005) was identified as having an impact in the broader context in three significant ways. First, although the oral history method was less ‘power exerting’ than some research designs, when accounts were considered together they had the propensity to become an authoritative political tool (Fingerroos and Haanpaa, 2012; Walmsley and Atkinson, 2000). It was important work because it generated some political interest and eventually overarching strategy was produced (Department of Health, 2008). This suggests that the research contributed to long term planning of services to provide end of life care to everyone within the National Health Service, whatever the condition and wherever the provision of care takes place.

Second the work by Clark et al (2005) was used to increase understandings about the development of hospices and has been cited by 36 scholarly works (Google Scholar, 2013). For example, the work of Bingley et al (2008) developing narrative research in supportive and palliative care drew on the history of Cicely Saunders, and the practice of listening to patients/families in order to understand their needs. O’Connor and Payne (2006) examined the use of discourse analysis in research and used ‘*A Bit of Heaven For The Few?*’ to highlight that there was much to learn from the analysis of text on the development of palliative care. One illustration was the creation of a shared identity and welcoming philosophy as well as the connections of policy and practice. Third, it has also been used as a source for the history of hospice and palliative care in academic texts for end of life education and doctoral research (Clayson, 2010). The intention of my research was to build on the work of Clark et al (2005) by using a similar method, furthermore to interpret accounts thematically and attempt to create links with social, historical and political mechanisms to reveal their impact on the development of services. However the focus of this study was on the detail in the local cancer and palliative care scene, and it also sought accounts from a wider group of actors than hospices.

Generating interest and collaboration

When cancer and palliative care services emerged in the United Kingdom health care planning and delivery were essentially ‘top down’ professionally led, and there was little attention paid to the patient. Traditionally, practices were steeped in the medical model where a linear perspective privileged the mechanics of disease (see chapter 2) (Kearney, 1992).

Conventionally, the National Health Service invested mainly in specialties that were seen to cure disease rather than provide palliative care (Murphy, 1990). It has been suggested that one reason for this was because dying was not seen as ‘normal’ and this denial spanned all ethnic, religious, and economic boundaries (Bowman and Singer, 2001; Demoratz, 2005; Seymour et al., 2004). It was problematic because most deaths occurred in hospitals but no specific provision was made for dying people there, palliative care had not been created as a specialty and the indication was that terminally ill people were neglected (Baines, 2012; Clark, 1999; Steinhauser et al., 2001). A further warrant for this line of argument came from Robert Twycross’ oral history (provided at the Witness Seminar on palliative medicine), which confirmed that hospice/palliative care development was a protest against such neglect (Overy and Tansey, 2012). Higginson (1993) also argued that hospices developed in response to ‘...poor treatment given to dying people by conventional care’ (Higginson, 1993, p.5) and were espoused to provide compassionate, holistic care that was unusual at that period (Saunders, 1965; Saunders, 1974; WHO, 2009).

In the course of time some voluntary organizations and statutory authorities worked together in a fairly cohesive way to generate interest in the field (Overy and Tansey, 2012). For example, in the case of St Christopher’s Hospice (in Sydenham), even before opening in 1967 Cicely Saunders had spent many years generating financial support from numerous charitable sources, as well as the Department of Health. This work shows four key elements: it demonstrates the importance of networking to generate support from those who could influence the development of services. Cicely Saunders’ activism was significant because it brought support for the project from Sir George Godber, Chief Medical Officer (between 1960-1973), Dame Albertine Winner, physician and administrator in the Ministry of Health,

Dr Gillian Ford Deputy Chief Medical Officer (in 1977) and Dr Richard Cohen, the first Chief Scientist at the Department of Health and Social Security (Overy and Tansey, 2012). Second, it was important for independent organizations to develop links with those occupying key positions within the National Health Service because their approbation resulted in the provision of much needed financial assistance. St Christopher's was able to carry out research into the relief of terminal cancer distress because Richard Cohen supported through 'special funds', the work of psychiatrist Colin Murray Parkes on bereavement (Doyle, 2005; Saunders, 2001b). Third, there was a need to integrate palliative care with oncology. Soon after St Christopher's had opened there were moves towards integration with oncology through the clinical oncologist Thelma Bates. Fourth, collaboration was important if the hospice was going to expand its work into the community. Mary Baines' oral history explained that in 1969 she started a home care service at St Christopher's, which she led as a General Practitioner with Barbara McNulty a senior nurse.

It was considered successful for three main reasons; first, because of the relationship that evolved between the hospice staff and those providing State services within the community. Mary Baines and Barbara McNulty had spent time speaking to general practitioners and district nurses to find out what they wanted. They then set about creating a service that went outside the hospice building to include the needs that had been identified - namely symptom control, support and counselling. Second, General practitioners remained 'in charge' of patients at home and district nurses did most of the basic nursing; the home service was available during the weekend and at night (24 hours service). Mary Baines' account states that it was different to the nine to five, five day a week service introduced by Macmillan (a cancer care charity) six years later because those providing services understood that the need for care did not arise during such a neat time frame. Third, Mary Baines stressed the importance of working with General Practitioners to reduce controversy and tension (Overy and Tansey, 2012). The process might well have been facilitated by Mary Baines' background in general practice and Barbara McNulty's in district nursing. It seems reasonable to suggest that there would have been shared understandings, objectives and respect between professionals that had done similar work. They would be more likely to understand the situation and what was required for developing services in the light of what they already knew from their past work

(as Nicolson and McLaughlin, 1988 found in their work on multiple sclerosis). In addition, hospice nurse Marjory Cockburn explained how the many personal links between individuals gave them the catalyst for change (Overy and Tansey, 2012). For example, Eric Wilkes had a background in general practice and was instrumental in developing palliative care at St Luke's Hospice in Sheffield the first hospice outside London (opened in 1971), and he had also trained at St Thomas' Hospital and knew Cicely Saunders.

Further developments took place in the 1970s when the Sue Ryder Homes services, administered by the charity Sue Ryder Foundation, emerged to provide palliative care for patients with cancer who lived in the charity's hospices/residential care homes. Several of these homes had nurses that could also attend to people in their own homes (National Association of Hospice Fundraisers, 2009; Sue Ryder, 2012). This indicates that there was now an attempt to provide more comprehensive services that covered home care, hospices and residential homes. Yet the focus continued to be on providing care for people with cancer, rather than broadening it to include those with a non-cancer diagnosis.

In 1974 the Royal Marsden Hospital opened the Horder Ward to provide specialized care for the dying and this signified two important developments. First, terminal care was separated from other forms of care. Second, in this prestigious National Health Service institution care of the dying was now considered important enough to have a ward dedicated to those needing care (Murphy, 1990). The next service to develop was day care, the first purpose built facility opened at St Luke's Hospice, Sheffield in 1975 (Winslow, Ostrovskis-Wilkes and Noble, 2010). There were by now about 25 hospice or palliative care services, many had close connections with their local communities because they depended on individuals to volunteer services and fundraise (Winslow and Clark, 2005). In 1975 there were other collaborative ventures between voluntary organizations and the State; physician Robert Twycross described how the vision of anaesthetist Ronnie Fisher led to the first Macmillan unit opening in Christchurch, Dorset after he asked Macmillan Cancer Support for assistance. It had a tremendous catalytic effect on the provision of palliative care because 'Continuing Care Units' were set up in Northampton, Southampton, Oxford and Northwood (Overy and Tansey, 2012).

Throughout the 1970s Macmillan provided capital grants for the building of palliative care units within hospital grounds (Macmillan Cancer Support, 2013). It could be argued that this was important because it created pressure, which engaged the National Health Service and secured more funding as Health Authorities had to agree to take over responsibility for the running costs of the units (National Association of Hospice Fundraisers, 2009). Therefore, in some places 'palliative care' received a share of the local health budget, the money remained within the National Health Service and nurses, doctors and the multidisciplinary team provided hands on care. It was probably quite an undertaking in terms of manpower/continued costs and because these changes developed sporadically. There were further difficulties because the Macmillan expansion coincided with a series of cutbacks within the National Health Service (Clark et al., 2005). Many Health Authorities could not see how if Macmillan raised the capital they would be in a position to meet the running costs of future projects. Yet in other places it brought a different way of thinking whereby Macmillan offered support to fund care in stages, and this fostered greater collaboration. For example, at Bristol, two nurses were provided to visit the radiotherapy unit and carry out home visits in conjunction with district nurses and general practitioners.

Greater cohesiveness

In 1977 the first hospital-based terminal care team was founded by oncologist Thelma Bates at St Thomas' Hospital (Overy and Tansey, 2012). Like the Horder Ward at the Royal Marsden, attention was also being directed towards care of the dying in another eminent London teaching hospital. Palliative care was gaining respectability and could now evolve in mainstream services. It is perhaps not surprising that such developments arose at St Thomas' Hospital because that was where Cicely Saunders trained as a nurse, social worker and doctor. Throughout the 1980s there were on average about 11 new hospices each year (Hospice History Programme, 2010). Work carried out by palliative medicine specialist Mary Baines found that when doctors were questioned about their motives for going into hospice medicine three themes kept coming up. First, many doctors were influenced by the bad death of an individual; others felt that poor care was not inevitable, and some said that hospice medicine

centred on the whole person/family not the diseased organ (Overy and Tansey, 2012). At the Witness Seminar on Palliative Medicine the reflections of psychiatrist Colin Murray Parkes and palliative medicine specialist Ilora Finlay revealed a sense of anger about the way people were treated, and the lack of training available. As young doctors they were taught not to get too close to patients because if they did they would suffer with them. A key problem with healthcare at the time was the focus on physical factors often at the expense of emotional needs (McIllmurray and Holdcroft, 1993; Mills, Davies, Macrae, 1994).

Clark et al (2005) identified that by the mid 1980s some voluntary organizations were also shifting towards a more collaborative way of working. One example of this occurred when Michael Carleton-Smith joined Marie Curie (a charity that provides nursing care at home) as Director General and began to establish working relationships with hospices. Now there was a vision of cooperation as the organization established working partnerships with hospices nationally, it brought revenue and more nurses to provide home care. Nurse Sally Campalani of the Marie Curie Centre, Belfast explained that this was very important because nurses provided practical care and stayed all night, rather than dipping in/out like Macmillan or district nurses. There were other signs that suggest different professional groups also worked more cohesively. For example, nurse and social scientist Jane Seymour confirmed that the achievements of Macmillan nursing were largely because of the strong partnerships that were forged between medicine and nursing, which enabled nursing leadership to take root (Overy and Tansey, 2012). Soothill and Thomas (1998) also found that similar collaborative doctor/nurse relationships empowered nurses and enabled innovative cancer support services such as complementary therapy to develop. This indicates that in time there was a 'coming together' of some cancer and palliative care services as they worked in a more flexible and cohesive way, although many organizations remained outside the National Health Service.

There were two wider developments that had the effect of bringing voluntary and statutory bodies together. First, the national charity Help the Hospices was formed in 1984 and provided a forum where activists could debate emerging issues, establish inter-hospice networks and provide a 'voice' for hospices (Clark et al., 2005). Second, by the end of the 1980s there was a

need for a more 'umbrella' type of organization that could represent the varied make-up, statutory/non-statutory, of the hospice and palliative care community. Therefore the National Council for Palliative Care was established in 1991 (National Council for Palliative Care, 2012). This was important because Help the Hospices was geared towards representing charities. There was also a need for an organization that would have the potential to gain the support of palliative care workers in the National Health Service as well as those at Macmillan, Marie Curie and Sue Ryder. The National Council for Palliative Care created paths for greater collaboration and sharing of precious resources between the independent and State services. It went on to develop standards and facilitate education, which were important steps in making palliative care credible and this is discussed in detail next.

1.2.1 The need for credibility

This section will show that it was important for palliative care to gain respectability and it explores some of the changes that took place in order to achieve this. Five key advancements were detected: oncologist Jane Maher argued that practising palliative care was not enough to gain the respect of other medical practitioners, a commitment to education was very important because of negative attitudes about the standard of terminal care (Overy and Tansey, 2012). This was also acknowledged by Jennifer Raimann (a psychologist that headed up the Macmillan medical services), who recognized that it was necessary for Macmillan to support doctors and nurses training because of the lack of state funding for palliative care education. It was problematic as some potential palliative care recruits felt vulnerable because of an absence of any career structure and academic respectability for the area (Small, 2000). This suggests that scholarship was a key factor in creating the knowledge and authority that was needed to make palliative care respectable (as Nicolson and McLaughlin, 1988 demonstrate in work on multiple sclerosis). Second, by 1985 a key group of early palliative medicine protagonists which included Cicely Saunders, Derek Doyle, Robert Twycross and Richard Hillier began to develop plans for an association to represent the interests of physicians working in palliative care (Clark, 2006). In October 1985 a meeting took place in Birmingham where 92 people attended and voted to form an association – The Association of Palliative

Care and Hospice Doctors (Overy and Tansey, 2012). At the Witness Seminar on Palliative Medicine, Richard Hillier explained that doctors needed a specialist palliative care body for political and professional reasons. Third, some prominent individuals such as the Queen, the Prime Minister and the Chief Medical Officer had visited a number of hospices. The Secretary of State advised Health Authorities to look more closely at the needs of the dying and the development of specialist services, there were hints that central financial support might be made available.

Fourth, in December 1985 the National Association of Health Authorities held a meeting in London which had considerable impact on thinking about hospice and palliative care developments. Doctors felt there should be structured training for palliative medicine (Overy and Tansey, 2012). Fifth, it appears that the Royal College of General Practitioners was not interested in making palliative medicine a specialized area of practice because it was felt that ‘they were doing it anyway’. Therefore Gillian Ford and clinical oncologist Kenneth Calman, who subsequently became the Chief Medical Officer, approached the Royal College of Physicians which granted subspecialty status in 1987 and that crystallized its respectability (Royal College of Physicians, no date). Clark (2006) argues that the formation of the medical association described, together with recognition of palliative medicine as a specialty and the establishment of a scientific journal ‘...conjoined to build a platform for the broad consolidation of the new field of activity...’ (Clark, 2006, p.6). There was much deliberation about the most appropriate name for the subspecialty (Doyle, 2005). ‘Hospice Care’, ‘Hospice Medicine’ and ‘Continuing Care’ were dismissed as being too ‘soft’ and ‘Palliative Medicine’ was chosen instead. There had been some discussion about whether to include ‘hospice’ in the title of the new journal but in the end it was called Palliative Medicine. Clark (2006) formed a view that as medical practitioners had taken on the responsibility of caring for those with end of life needs, in the course of time the medical model would exert growing influence on practice.

In addition, doctors who were members of the Royal College of Physicians, Royal College of Radiologists and Royal College of Anaesthetists could become members of the sub specialty.

Within a few years those who were members of the Royal College of General Practitioners were also accepted to specialize in palliative medicine. This demonstrates that from the beginning the specialty was multidisciplinary and as such brought a range of perspectives to the field. It is likely that the training/background of doctors from different disciplines would have impacted on their approach because they would perceive palliative medicine from the perspective of their specialty, as Nicolson and McLaughlin (1988) found in their work on multiple sclerosis. By way of illustration, this suggests that General Practitioners like pioneer Eric Wilkes had the ability to perceive palliative medicine from the structure of general practice. It also intimates that those with a similar background would be more likely to have an interest in developing palliative medicine in the community, as they were experienced in caring for people at home (Report of the Working Group on Terminal Care, 1980; Winslow, Ostrovskis-Wilkes and Noble, 2010). Yet as palliative medicine was not narrowly focused like conventional specialties and it did not have a specific disease to treat, this created tension because some could not see how it differed from other areas of general medical practice (Fordham, Dowrick and May, 1998; Overy and Tansey, 2012). Questions were raised as to why a subject whose principles were an integral feature of all good clinical care needed specialty status. Doyle (2005) responded that there was a need for palliative medicine to address physical, psychosocial and spiritual suffering for which most doctors had no training.

Very quickly the medical discipline of palliative medicine developed a four-year specialist-training programme. This was due in part to considerable help from Macmillan Cancer Support, in the form of 'pump-priming' grants to set up new Senior Registrar Training Programmes. In 1991 the first wave of ten posts were inspected and approved by the Joint Committee on Higher Medical Training of the Royal College of Physicians. Another reason for these relatively speedy developments was because Deputy Chief Medical Officers (Dame Albertine Winner and Dr Gillian Ford) were also 'on the rota' at St Christopher's, Gillian Ford explained that this was clearly useful because it promoted the hospice work (Overy and Tansey, 2012). There were three significant reasons identified as to why these changes brought the independent organizations and the National Health Service another step closer. First, they now had shared objectives about professional training, practice and policy; second, those working in hospices were affiliated to the same professional body as those working in

the National Health Service. Third, becoming a specialized area of medicine meant that there were now more consultant posts and training posts in the National Health Service (Overy and Tansey, 2012). In the early 1990s the first university chair in palliative care evolved to develop the academic field and increase research based evidence, which brought further collaboration and respectability (Clark, 2006). The Government issued a Health Service Circular in 1998, which endorsed recommendations from the National Council for Palliative Care for improved care in hospitals. It encouraged more hospital teams with specialists in palliative medicine, nurse specialists and administrative support (Doyle, 2005).

These data would suggest that generally in the course of time the relationship between the voluntary sector and the state became closer, this advanced medical education and eventually palliative care became an academic discipline with a greater research base. Moreover, it is likely that the academic progress brought further authority to the specialty (as Nicolson and McLaughlin, 1988 found in discussions about the aetiology of multiple sclerosis). I have discussed how the oral accounts from the Witness Seminar illuminated the history of palliative medicine. Yet from a critical perspective those who attended the meeting determined the discussions. There might have been different facets to the story that were not revealed during the discussion as Berridge (2010) found in relation to the Witness Seminar on haemophilia. Craggs and King (2013) argue that recollections are always 'partial' because they are created in the past and shaped by the present (see chapter 2). I will move on now to explore various perspectives in relation to the way facilities were evolving.

1.2.2 Differing views appearing about the direction of services

The development of the modern hospice has generally been accepted as a considerable success story for the reasons that I have discussed (Small, 2000). In time many general practitioners came to champion hospices, yet there were others who resisted because they believed patients could be better served by a collaboration of doctors, nurses and social workers (Moore, 1973). Moore (1973) argued that general practitioners should remain 'in charge' and be able to access

hospital beds for the ‘challenging’ cases rather than involve staff from specialized hospices. Further disquiet was highlighted in the Hospice History Project, Dr Cook and Dr Edwards described how they met enormous opposition from the medical profession in the mid 1970s. Colleagues were aghast that anybody should imply criticism or suggest that standards were not all they might be; others felt however little the service cost it would be taking away their slice of the cake (Small, 2000). Palliative medicine specialist Geoffrey Hanks, argued that one reason why some individuals did not think that a hospice was a good idea was because in the early days it became apparent that the number of patients seen by hospice/specialist palliative care staff was limited (Overy and Tansey, 2012). Douglas (1992) was more pejorative and claimed that ‘...the hospice movement was too good to be true and too small to be useful’ (Douglas, 1992, p.579). Douglas (1992) questioned why care at the end of an illness should be separated from all that had gone before, why those with malignancies should receive special treatment and why such a large need should be left to ‘a patchwork’ of local charities. There were calls for the National Health Service to take charge and develop palliative care support units, which could offer consultations and home care services with a few beds for the most difficult cases. I have explained that Saunders (2000) formed a view that it was necessary to create special facilities outside the mainstream services because those services did not see hospice and palliative care as important areas of work. Furthermore, according to Doyle (2005) there was a need for palliative medicine to meet the physical, psychosocial and spiritual needs because most doctors were not trained to provide this kind of care.

Yet some of the pioneers themselves also began to question the expansion of hospices. Eric Wilkes Chaired the Working Group on Terminal Care in 1979, which emphasized that techniques were available to alleviate the worst miseries for patients without the need for new buildings or expensive equipment (Report of the Working Group on Terminal Care, 1980). According to Geoffrey Hanks, Wilkes was particularly concerned that palliative care was not achieving the coverage required because it was not available to the number of patients who needed it (Overy and Tansey, 2012). This appears to have been the key to bringing about a change of thinking because he believed that energy and finances needed directing towards the National Health Service where most people received care. Palliative care provision was needed on a much larger scale to reduce inequitable access to these services. This report shows

six key elements: First, getting the help required depended on ‘enlightening’ professional attitudes. Second, it recommended high-quality nursing care, counselling, physiotherapy, spiritual, social and occupational/recreational therapy because it was thought that these inputs would enhance life. Third, questions were raised about the high number (59%) of deaths that continued to occur in hospital, and attention was drawn to the low number (5%) arising in non-National Health Service hospitals and hospices. There were concerns that hospices were only reaching a small number of people. Furthermore, the figures possibly reflected over-optimistic prognosis, relatives’ unwillingness to accept the imminence of death or their lack of confidence about coping. Fourth, Wilkes argued that the way forward was to encourage the dissemination of the ‘principles’ of hospice care throughout the health service, because that was where most people received care. Therefore the district general hospital was seen to have a significant role to play in providing expert advice on pain control and symptom relief. Fifth, it advised that existing hospices should become the initiators of new approaches to symptom relief, centres for research and play a role in training general staff.

Sixth, high quality primary nursing care was required to care for the terminally ill. The report recognized that local needs might vary, in rural areas travel to a special unit was often more difficult because of the lack of public transport. Therefore it recommended more home care services in those communities. It suggested that in cities there was probably a greater role for a specialist unit because many people lived alone; therefore the provision of home care was often more challenging. In addition public transport was likely to be available to transport people to a palliative care facility if necessary. This was an important key development that signified for the first time that there was a need for a national framework for palliative care. It urged every regional health authority to plan for terminal care provision and incorporate palliative care training at nursing and medical school (Help the Hospices, 2013). I would qualify this though because the report did not acknowledge that a home death could be challenging if the patient was young, and there were children living at home. Furthermore, it raised concerns about out-of-hours services being provided by a deputizing service and concluded that it was not compatible with the commitment required in good family practice. It must be remembered that general practitioners did their own on call at this time. The Working Party believed that home care could be achieved if practitioners gave their home telephone number to the family, so they could contact a professional in the night for support.

Nonetheless, setting these issues aside, this was the first national report to set out ‘top down’ recommendations for care at the end of life and which harnessed some political interest. In 1987 the Department of Health issued a Circular that required Health Authorities to examine their arrangements for terminal care (Higginson, 1993). Now it was possible that the work of the hospices would find its way into the strategic planning of National Health Services. By this stage there had been striking achievements because there were over 200 inpatient hospices, day care centres evolved, domiciliary care services expanded and there were growing numbers of specialist hospital teams (Small, 2000). Yet despite the intention of the Working Party on Terminal Care to provide palliative care for all within the National Health Service, this was not achieved during the period of my study (Winslow, Ostrovskis-Wilkes and Noble, 2010).

Tension also began to emerge about the way services were developing from within palliative medicine. James and Field (1992) highlighted that hospices became increasingly subject to mainstream influence leading to routinization, bureaucratization and professionalization (see chapter 4 for discussion). Kearney (1992) cautioned that palliative medicine could become ‘...a specialty of “symptomatology”...confined to the limits of the medical model...’ (Kearney, 1992, p.39). Yet this was not what the pioneers of the modern hospice movement had had in mind because they initiated developments that could ‘...be seen as a compassionate response to needs not being met by western medicine’ (Kearney, 1992, p.40). Reflecting on experiences at St Christopher’s he commented that although many patients died within a few weeks it was a place of ‘curing, healing and caring’ because of the humanity of the people in the team. Whilst palliative medicine had raised its profile through its ‘specialist status’, there was some uneasiness because there was now a need on the part of some doctors to conform to the medical model. One reason for this was that the paradigm was familiar, and following it would be more likely to generate respect from other professionals. Yet such practice could miss opportunities to find holistic ways of enabling a person to discover something of value in the short time left which might be essential for healing (Kearney, 1992). For example, there could be a way of helping an individual to form a better relationship with a relative so that they were enriched by the experience, as the following extract from a patient’s reflection illuminates:

‘We feel privileged to have been granted precious time for laughter, for tears and for sensible preparation for the inevitable’ (Glyn Harris cited by Quainton, no date, p.15).

My study connects with these illustrations because I had a number of questions pertaining to the philosophy of those providing cancer and palliative care, and also in relation to how care was provided at the end of life (see Introduction and chapter 3).

Different perspectives were also held by those in the acute setting about the way services had evolved, and it was felt that there was a need to bridge the gap between hospital and home care. For example, at North Tees Hospital in North East England it was mooted that one way of achieving this was through greater liaison between consultants, general practitioners, district nurses and carers. There was some tension in relation to the growth of hospice units, which were considered unnecessary because ‘hospice’ was perceived as a philosophy rather than a place set in bricks and mortar (Morris, 1981). The local hospital at North Tees was running on a bed ‘under occupancy’ of around 30 percent, so providing terminal care beds appeared more logical than building hospices. Care could then be provided in the National Health Service based on need rather than a cancer diagnosis. One critical point to make is that what was preferable at North Tees might not have been achievable in other places because different areas were heterogeneous so had their own needs and resources. Other concerns about the expansion of services outside the National Health Service came from within the specialist area of practice. The main worry was that charitable giving was only short term but a long term plan was needed. William Notcutt was a Consultant Anaesthetist at the District General Hospital in Great Yarmouth in the early 1980s, and he developed a passion to improve care of the dying (Overy and Tansey, 2012). Although the model of palliative care at the time evolved around hospice, Notcutt realized that he would have to take the hospice to the patient because there was no money to build a hospice. Therefore, a palliative care team developed within the pain service of the local hospital. Notcutt was of the opinion that care should be for all patient’s not just those with cancer, this was unusual because hospices mostly cared for people with cancer. In the late 1980s various groups tried to raise funds to build a hospice but Notcutt underscored three reasons as to why this should be resisted. First, in his experience most patients wanted to die at home. Second, a hospice would need funding

entirely from charity but this was not a wealthy community. Third, it was felt that a hospice unit would take nurses out of the hospital to provide high quality care to a small number of people. On a critical point Notcutt's account suggests that it was idealistic to expect a palliative care service from those who were not working within the specialist field. One illustration of this was that by 2002 he and his colleagues were still 'agonizing' about the care delivered locally. The conclusion reached was that the hospital did need a palliative care unit to improve the management of complex problems. Furthermore, this unit was staffed by nurses from the hospital and the palliative care team also relied on charity. Nevertheless, Notcutt had been keen to avoid these kinds of developments and he did not support a hospice unit initially. This kind of dilemma highlights some of the complexities faced and how they were dealt with in time by negotiations and compromises. It illustrates that in the course of time, palliative care services continued to develop in National Health Service hospitals.

Lunt and Hillier (1981) conducted a survey, which identified 72 services that provided 58 inpatient units, 32 home care teams, and 8 hospital support teams. It also found considerable regional variations because some areas had four times as many inpatient beds as others, yet Wales and five English regions had inadequate provisions. The number of home care nurses was the lowest in the southwest and the north; calls were made to redress imbalances by prioritizing the development of home care teams. The researchers stressed that hospital support teams had the potential to make the greatest impact on care, without the capital costs incurred by inpatient units, and they recommended additional training of staff. This work revealed the heterogeneous nature of palliative care services. It suggests that the variations in resources emanated from a lack of long term planning. Consequently, the researchers continued to question whether further specialist services were the best solution (Lunt and Hillier, 1981). Having explored the development of palliative care I will now examine the history of cancer services.

1.3 State of cancer facilities

In this section I explore the status of cancer services, investigate the progress made by professional bodies including the Association of Cancer Physicians and the Royal College of Physicians, and indicate how they impacted on the development of cancer services.

1.3.1 Cancer services

Prior to the emergence of medical oncology surgery was generally the first line management for cancer, clinical oncologists offered radiotherapy when surgery was no longer seen as curative. Radiotherapy was conventionally available at one major hospital in each region, and cancer centres developed around them without any long-term planning or consideration of geographical or population requirements (Murphy, 1990). Most were concentrated in London and thinly spread in other places. For example, in the North West there was only one centre providing services, which meant that people in that region might travel up to 140 miles for radiotherapy (McIllmurray, 1992a). Whilst radiotherapy had evolved for those in whom surgery was not an option, historically medical treatments for cancer had not commanded the same respect because they were not seen as having a valuable contribution to make to scientific medicine (Murphy, 1990) (see chapter 2). Nonetheless, attitudes began to change as a result of the work carried out in the 1950s by Cancer Research United Kingdom into the use of nitrogen mustard. It led to the development of alkylating agents and antimetabolites, which were some of the first chemotherapy agents in Britain to treat leukaemia, myeloma and lymphoma. In 1977 the first platinum derivative cisplatin was approved for use in patients with testicular cancer and was later used to treat other malignancies. These chemotherapy agents were often used in combination to treat various cancers, and some physicians began to specialize in medical oncology (Cancer Research UK, 2012; Wellcome Trust, 2009). The field of medical oncology was first acknowledged by the Royal Colleges in 1980; initially doctors developing this area worked in close collaboration with biomedical scientists based at universities and cancer centres. In the early days the focus was mainly on research and the

introduction of biological agents and cytotoxic drugs into clinical practice (Bennett et al., 1996). In 1985 the Royal College of Physicians recognized medical oncology as a specialty, and established the Association of Cancer Physicians to represent medical oncologists and raise ‘...the standards of medical care for cancer patients’ (McIllmurray, 1987, p.117) (Association of Cancer Physicians, 2012).

This suggests that as a general point collaboration with those engaged in conventional forms of research increased the respectability of medical oncology (in a similar way to the multiple sclerosis work of Nicolson and McLaughlin, 1988). In addition, the creation of medical oncology as a specialist field impacted on the development of services because individuals with cancer were now segregated from those with other medical conditions. For example, they had access to medical oncologists and could receive special treatment. Yet two factors were identified as creating some degree of strain: First, there was a lack of facilities at district level and second because chemotherapy was confined to a few centres. Opinions were being vented that centralization was ‘...hopelessly inadequate for delivering the range of treatments, support and care that was needed’ (McIllmurray, 1992a, p.62). Pressure was also rising because many people were not being given the best treatment, as they did not have access to a cancer specialist locally. However, since medical oncology did not require any particular expensive equipment, other than the cost associated with medication, there was a line of argument that there was no reason why it could not be provided at district level. There was a general consensus that radiotherapy should remain centralized because it was costly and required specially trained staff (Association of Cancer Physicians, 1994). The Association of Cancer Physicians commissioned a working group at the end of 1985 to make proposals for the development of cancer medicine at District General Hospitals. There was concern about the poorly integrated and un-coordinated service, which was inequitably distributed across the country. Some individuals travelled long journeys for treatment which could be tiring, isolating, expensive, inconvenient and distressing due to side effects of drug toxicity. Families often had the added financial burden of transport and hotel costs, which could be difficult if the person with cancer was also the main wage earner (McIllmurray, 1987). It was argued that many of these problems could be overcome by developing medical oncology at district general hospitals. At the time there were 191 Health Districts in England and Wales but only eight had

appointed 'general physicians with an interest in medical oncology'. These were in Bradford, South East London (Brook Hospital), Derby, Lancaster, Stevenage, Poole, Bath and Wigan. A few support organizations had also emerged; CancerLink in London, CancerCare in Lancaster and Tak Tent (which means 'take care') in Glasgow. The latter was developed in the 1970s by Kenneth Calman to provide support to families of patients with cancer (Overy and Tansey, 2012). These organizations turned out to be important developments in the whole ethos of cancer thinking as I shall come on to explain later in this chapter.

In 1985 the working group of the Association of Cancer Physicians made three key recommendations. First, all patients with cancer should have easy access to a cancer physician; second, districts with a population of 250,000 or more should appoint a cancer physician, third, those with a lesser population but more than 30 miles from a regional centre should also appoint one. The proposals, if fully implemented would increase the total number of district cancer physicians to 63. In 1986 they were endorsed by the Association of Cancer Physicians. The plan was that cancer physicians would liaise with other cancer physicians in the region to apply agreed protocols. They would set up outpatient facilities, initiate/develop support services which would include the family and create palliative and terminal care services. General physicians and surgeons had up until now provided treatment to those with cancer. Therefore the proposals were significant because as well as increasing the number of specialists, there was a shift away from generalists care to specialist treatment.

Notably, there was an expectation that medical oncologists would begin to develop terminal care, yet conventionally the focus had been on curing the disease (see chapter 2). For example, as part of the comprehensive service the district cancer physicians would ensure that there were '...appropriate arrangements and facilities for supportive, palliative and terminal care...The continuing care of patients with cancer must include management of the terminal stages of the illness...this could become an additional responsibility for the District Cancer Physician' (McIllmurray, 1987, p.118). Similarly, an important principle that was identified as underpinning the Association of Cancer Physicians model for cancer services was the need to provide care from diagnosis to terminal care, and to have direct access to palliative care

facilities (Association of Cancer Physicians, 1994). Services were now developing in a dynamic way, they did not focus on a particular 'stage' of cancer but instead it was recognized that care was needed at all stages. In order for services to be comprehensive there needed to be some continuity of care from diagnosis to the end of life, as well as collaboration between organizations. Although a plan had now emerged these recommendations were largely ignored, by 1991 no new district consultant posts had been established and cancer specialists themselves could '...not agree about the best way forward' (McIllmurray, 1992a, p.63). In any event, universities or charitable sources such as Macmillan Cancer Support funded most of the medical oncology posts that did exist because there was still no proper commitment from the state (McIllmurray, 1987).

A report by the Board of the Faculty of Clinical Oncology highlighted huge deficiencies in manpower and also called for more cancer specialists (Board of the Faculty of Clinical Oncology, 1986 cited by McIllmurray and Holdcroft, 1993). Nonetheless, activists argued that the recommendations did not go far enough because as well as requiring more specialists, they needed to expand their role so that it also included supportive and palliative care at the district level. There was a growing social awareness among the public of the benefits these kinds of services could bring. It was felt that a collaborative approach between the voluntary sector and Health Service offered a way of meeting the rising demand for the provision of supportive services alongside conventional care.

Despite the work that had by now been done by the professional organizations, little was known about the distribution of services aimed at helping people to cope with cancer. Therefore in 1991 Addington-Hall et al (1993) carried out a national survey of support services provided by district health authorities. They found that out of 190 health districts six provided no services at all and 16 provided practical support such as physiotherapy, mastectomy and stoma care. One area provided emotional care (counselling and support groups). Ninety four provided both types of support and 53 provided complementary therapy (meditation, relaxation, healing and art therapy) as well, but only 32 districts provided all of the support. Less than 20 percent of authorities were providing a full range of support services

(practical, emotional and complementary) and there were wide variations across the country. Once again this suggests that such heterogeneity was down to the lack of long term planning. On the other hand it also demonstrates that emotional needs were being taken seriously in just under half of cases (practical and emotional care). On a general note emotional needs were now being addressed in the National Health Service albeit in a disjointed way. Those responsible for purchasing were urged to provide facilities aimed to meet physical and emotional needs. The wide discrepancies identified had led to fragmented, poorly coordinated services and of course there was still no agreed strategy at this time (Addington-Hall et al., 1993). From a critical perspective the study was limited because it used postal questionnaires, respondents would have been restricted by the answer choices which might not have reflected their experience but they were required to choose one. However the response rate was high at 89% which increased its reliability, it would have been even more interesting if it had been followed up with interviews to uncover details about the nature and accessibility of services.

The recommendations made by the working group of the Association of Cancer Physicians to expand medical oncology at the district level ‘...had not found much favour with clinical oncologists’ (McIllmurray, 1992a, p.63) (McIllmurray, 1987). Clinical oncologists were radiotherapists who delivered radiotherapy; medical oncologists were physicians who administered chemotherapy but not radiotherapy. Two key points of note here were that the Association of Cancer Physicians represented the interests of medical oncologists not clinical oncologists. Second, they recommended that medical oncologists should develop district cancer services, which was an important change because conventionally clinical oncologists had provided treatment in the radiotherapy centres. This created tension, Sikora (1992) argues that there were serious anxieties about inequities and the variation of standards across the country, he was a proponent of centralized cancer services (medical and clinical) to provide ‘...the best care’ (Sikora, 1992, p.61). Nonetheless, the Association of Cancer Physicians (1994) identified that the historical way of organizing cancer services around radiotherapy centres was by now outdated. It recommended, *inter alia* that a cancer centre should be attached to a radiotherapy facility because it recognized that this service was needed to provide complex treatment. It advocated expansion at district level for the more common cancers in areas with a population of 300,000 or more that were greater than 30 minutes away

from a centre (or smaller populations that were more than 60 minutes away). There was a need to increase substantially consultant positions in these units; around 45 new posts were required which would make a total of about 53. Additional posts at smaller hospitals were required if they were long distances from cancer centres. These needed to link up with cancer centres, at least eight consultants were required to maintain expertise at the centres; oncologists from smaller hospitals and the centres could then meet regularly for education and audit. The role of the cancer support nurse was seen as essential for the delivery of a comprehensive district service in hospital, home and hospice. Likewise palliative care was considered vital and provision should be made for this in the cancer unit or provided through liaising with specialist services. I will now explore the policy that subsequently evolved to provide a long term plan for cancer services.

1.3.2 Leading framework

The first major policy that provided an overarching plan for cancer related services came in 1995 when the Calman-Hine report was published (Department of Health, 1995). It followed The Health of the Nation White Paper, which identified that preventative and screening measures had the potential to reduce deaths from cancer (Department of Health, 1995). There were concerns about the incidence of rising cancer rates as well as variations in recorded outcomes of treatment. The policy provided a framework to address inequities by creating a network, which aimed to enable a patient anywhere in the country to be sure treatment and care were of a uniformly high standard. There were three key proposals: First, the emphasis for care was on the need for site specialization. Second, multidisciplinary teams would provide palliative care and psychological, social and spiritual support. Third, ideally services would provide access to screening, early diagnosis and the best available management in the most convenient location. These resources should be as close to home as was compatible with high quality, safe and effective treatment. My study aimed to place the research findings in the wider context of cancer and palliative care issues, and to increase understandings about the development of cancer and palliative care provision in the course of time (see research aims 3 and 4 in Introduction). This wider policy was relevant to addressing these aims. I explained

earlier that in the late 1970s care was professionally led; however by 1995 policy advocated more of a patient centred approach taking into account families and carers' views. Yet by this stage many at the grass roots of cancer and hospice work had already been practising in this way for more than 30 years (Saunders, 1996). The Calman-Hine Report proposed three levels of care; *primary care*, the creation of *cancer units* in many district general hospitals for the common cancers and *cancer centres* to provide specialized expertise and radiotherapy. All cancer units should have a lead clinician with an interest in cancer care to coordinate services, and link up with the cancer centres. Units were advised to include palliative consultation, access to counselling and appropriate complementary therapy, self-help groups, physiotherapy, social services and other facilities provided by the multidisciplinary team. One further endorsement was that palliative care should not be associated exclusively with terminal care because some people needed it from the time of diagnosis. The overarching aim was to try to integrate cancer and palliative care services at home, in the community and in hospital. The concerns voiced earlier about the *ad hoc* way many palliative care services evolved were echoed here and more incorporation was called for. Where new developments were proposed, it was recommended that local needs should be assessed first to ensure services would not be duplicated and would satisfy unmet needs. In short, it was a landmark set of recommendations.

In 1998 a study was carried out by academics based at Lancaster University, which reviewed the development of cancer support services in Lancaster (Soothill and Thomas, 1998). It used qualitative personal accounts of events written by the key actors constructing these services (Bryant et al., 1996). Soothill and Thomas (1998) aimed to consider how suggestions for the restructuring of cancer facilities (in the Calman-Hine Report) had been addressed in Lancaster. They focused on recommendations that related to the development of an integrated service of primary care, cancer units and cancer centres, as close to the patient's home as possible. They also looked at the promotion of patient centred care to address psychosocial issues (see chapter 5). The research revealed that the area had actually had facilities that were akin to several of the proposals in the Calman-Hine Report for a number of years, for example there was a cancer support organization, a hospice and an oncology service. Furthermore, individual and social mechanisms had impacted to shape services; key actors (Cancer Support Nurse and Consultant) were willing to take psychological needs seriously and provide supportive care,

including complementary therapy. In addition they were reported to ‘...enthusiast and win the commitment of others, and...break new ground’ (Soothill and Thomas, 1998, p.70). Working relationships were informal between the actors, which allowed ideas from the nurse to emerge and shape developments. The protagonists posited that as there were no existing facilities ‘...there were no vested interests in the health care services or the voluntary or community sector to clash with, no failed precedents and no ‘we can do it better’ champions to make the developments difficult...’ (Soothill and Thomas, 1998, p.70). The proponents of the Lancaster services had published a report in 1986 outlining the development of these facilities (McIllmurray, Gorst and Holdcroft, 1986). They argued that one way of improving care for patients with cancer was by centralizing radiotherapy services and developing medical oncology, cancer support services and terminal care in the districts. Soothill and Thomas (1998) refer to the article by McIllmurray, Gorst and Holdcroft (1986) as an ‘official version’ of events. However, they were also of the view that the main participants had been too modest of their contribution and failed to recognise the complex interaction of individual, circumstantial and social factors on the developments.

The intention of this study was to reveal similarities/differences, and to build on this work by exploring accounts from a wider group of actors than those that had been involved in the cancer and palliative care services in the Lancaster area. Soothill and Thomas (1998) confirmed that no tensions were revealed in their study but ‘...it became apparent how the multiple realities of...people engaged in the enterprise had been squeezed into that ‘official’...version’ published in 1986 (Soothill and Thomas, 1998, p.69) (Peniston-Bird, 2012). On a critical note the study used written accounts constructed by the key players and they might have painted a more positive picture than others would have done, since they were the proponents and still involved with the services. In addition, there was no opportunity to probe for information or clarify interpretation of the written accounts. The study would have been even more engaging if it had followed up the ‘memoirs’ with interviews and included actors from a wider group, for example in hospice and palliative care and this was acknowledged by the researchers.

By 2000 cancer services in the United Kingdom were getting a lot of media attention because there was evidence to suggest that cancer survival rates, for patients diagnosed in the previous decade, remained lower than other European countries (Department of Health, 2000). The policy makers identified two key reasons for this. First, it was probably because of inadequate investment and planning of services which made access to specialists inequitable. There were insufficient numbers of consultants and inconsistent ways of assessing the services offered. Second, these issues together with wider social factors impacted on health and wellbeing, as those from deprived backgrounds were more likely to suffer and die from particular types of cancer. The primary risk factors were identified as being the same as for coronary artery disease, namely – smoking, poor diet and deprivation. Therefore the focus was on prevention, screening, faster diagnosis/treatment, improving the quality of services and increasing life. The approach was well overdue because it came 20 years after the link between being poor and morbidity and mortality in relation to health inequalities in cardiovascular disease was known (Black, 1980). The National Health Service Cancer Plan advocated the need to standardize quality to improve survival and quality of life (Brown and McIlmurray, 2000; Department of Health, 2000). It was committed to reducing inequalities through:

‘...national and local targets for the reduction of smoking...waiting times...standards for cancer services...investment in specialist palliative care...expansion and development of the...workforce...facilities, and...research’ (Department of Health, 2000, no page).

The strategy pledged an extra £50 million a year until 2004 for hospices and specialist palliative care, a move that was designed to improve access to services across the country. There was also an intention to ensure that when the National Institute for Clinical Excellence published guidance on 13 new cancer drugs, Health Authorities across the country would be able ‘...to take full account of it’ (Department of Health, 2000, p.13) and more chemotherapy would become available. From a critical perspective there was no mention of what should happen if an oncologist in a local area recommended a different drug to that on the ‘list’, or whether in those circumstances it would be available. However, looking at the wider picture

there was a promise to provide funding to pay for more chemotherapy and specialist palliative care services in the community, hospitals and hospices. It was the most extensive programme to date to shape the direction of cancer and palliative care services because it called for expansion in all areas and aimed to make facilities more comprehensive. Moreover, it provided a commitment to fund them.

This policy also advocated directing resources towards developing community services, and it therefore resonated with similar recommendations in the Report of the Working Group on Terminal Care (1980) (see 1.2.2). Furthermore, it changed the emphasis of care from hospice units to community services because it pledged a further New Opportunities Fund initiative for community palliative care services. Now it was envisaged that primary care would play a central role and ensure that more development occurred in the community. It was important because by 2000 only a third of Health Authorities had developed strategies and so services remained uneven. For example, too many patients still experienced distressing symptoms and poor nursing care (Department of Health, 2000). Careful scrutiny revealed that two important principles were embedded in the policy. The first was to forge a closer network between voluntary sectors and state services. Second, it was also to bring the ‘hospice’ and ‘palliative care approach’ within the National Health Service by using district nurses and general practitioners to expand services to more people. Yet there was some tension between these approaches which I explore next.

1.3.3 Tension: hospice, cancer and palliative care approaches

It is commonly accepted that the philosophy underpinning palliative care had its roots in the modern hospice movement, in particular the concept of ‘total care’ which aimed to facilitate a ‘good’ death (Kearney, 1992; Saunders, 2003). The philosophy underpinning oncology was more about ‘living with cancer’, and it also aimed to increase understandings of the emotional and social factors that impacted on those with cancer. Technical competence in cancer management had been important in the early days because it brought respectability and

ensured the field had a research-base (Nicolson and McLaughlin, 1988). In the course of time the need for psychological care began to be acknowledged and four key factors were identified in bringing about this change. First, I have explained that the support groups were important in the whole ethos of cancer thinking. Much of the psychological distress suffered by individuals with cancer was found to peak early on as soon as a cancer diagnosis was suspected; therefore cancer support services were needed from the time of diagnosis (Smith, 1990). There were also wider social consequences of a cancer diagnosis, for example as illness progressed individuals often suffered loss of employment, reduced income and their social life was curtailed. Greater awareness of these problems led to the establishment of support groups which were often initiated by patients themselves outside the National Health Service (McIllmurray, Gorst and Holdcroft, 1986). These groups were frequently operated by volunteers or 'professionals' acting in a voluntary capacity who provided information about diagnosis, treatments, health promotion and living the best quality life possible. Some early illustrations have been given such as Tak Tent, CancerCare and CancerLink, there was also Backup (in London) and the Bristol Self Help Clinic (McArdle et al., 1996; Overy and Tansey, 2012) (see also chapters 4 and 6). Second, complementary therapies were also developing in prestigious institutions such as the Royal Marsden Hospital (Smith, 1990). In addition techniques were being created to improve communication between health professionals and patients, for example the oncologist Rob Buckman and psychiatrist Peter Maguire developed educational courses (Youren, 2007). Third, this change in focus also arose because patients became more assertive and rightly demanded information and better support (Bennett et al., 1996). Fourth, this ethos was also reflected in the emerging strategy which recommended the provision of psychosocial care (Department of Health, 1995).

There were signs that some practitioners developed hospice care as well as cancer support facilities because they aimed to provide a 'complete' service (McIllmurray et al., 1992). Furthermore, a holistic approach combined cancer treatments with supportive care including complementary therapy and the hospice was introduced at an early stage. Others acknowledged that cancer caused a great deal of stress, but argued against the provision of policy to support all patients with cancer (Watson, 1983). Instead it was suggested that supportive care should be made available to those considered at risk of psychological

morbidity. There was some tension in relation to the difficulty of evaluating such care because the advantages of one type of support over another remained ‘...unproven’ (Watson, 1983, p.839). From a critical viewpoint Watson (1983) observed that some studies did not make an objective evaluation, and outcomes were often based on comments made by patients who found a programme useful. Therefore it was not surprising that conclusions about the effectiveness of a therapy were favourable. These perspectives probably reflected the period; in 1983 it was not usual to study the subjective experiences of patients to ascertain what they perceived was beneficial or unhelpful. When these new cancer supportive therapies developed there was not an established evidence-base. That was also evolving and of course it did not develop in a linear way like conventional practices so that created tension (see chapters 2 and 6).

I have explained that Macmillan Cancer Support had a major impact on the progress of cancer services through the collaborative ventures with the National Health Service and contributions made to the capital costs of cancer units. The charity was also very important in developing education because it supported many educational programmes for doctors and nurses training in oncology. It also funded nursing posts and consultants positions across the country; it was not unusual for the organization to contribute around 50 percent of the cost (Bennett et al., 1996). There were also other signs that suggest Macmillan had a significant influence on the provision of supportive care that took wider social factors into consideration. For example, Macmillan provided social and health benefits advice for those suffering loss of income/unemployment because of ill health (Macmillan Cancer Support, No date). This shows that services began to develop in such a way that took the broader impact of illness on daily life into consideration. The public also became much more questioning and demanded better services with more information. In the course of time their social needs became more widely acknowledged, and the provision of information became one of the major tasks of cancer services. Moreover this suggests that education contributed to better informed patients who then became increasingly involved in decisions about their own treatment (Tattersall and Thomas, 1999).

I have discussed that the overarching strategy advocated greater cohesiveness between cancer services and palliative care (Department of Health, 1995; Department of Health, 2000). Yet evidence suggests that there was some tension between medical oncologists and palliative medicine specialists. By way of illustration Bennett et al (1996) presented contrasting views about training/practices in oncology and palliative medicine, which demonstrated that there was a degree of strain at times. Some oncologists argued that training in oncology for a minimum period of six months should be obligatory for palliative medicine trainees because most patients referred to them had advanced cancer. In addition, there was growing evidence that palliative chemotherapy and radiotherapy could improve the quality of life for some individuals. The thinking was that a sound knowledge of this would enable doctors to properly inform patients of their choices. It suggests that greater collaboration between the professions would go some way to ensure that doctors were up to date with advances, and in turn patients would have more autonomy in relation to decision making. Yet the fundamental difficulty now was that those in palliative medicine were trying to expand the service to everyone with palliative needs, so there was some resistance to this kind of proposition.

It could be argued that palliative medicine was possibly being shaped by oncology as advances were made in that specialty. There were also tensions between oncology and palliative medicine because of the limited research base of the latter. This added further impetus to the argument that if palliative medicine trainees spent time in oncology the exposure might demonstrate the benefits of collaborative research. Moreover, the authors pointed out that any modern medical specialty should be able to justify the therapies it used to patients, professionals and purchasers. In any event job descriptions of recently advertised consultant's posts demanded some oncology experience, so it appeared logical to collaborate in relation to training. This indicates that wider social and professional factors impacted on the shape of palliative medicine and this was also a strain. For example, those at the grass roots of hospital medicine drove the change towards recruiting palliative medicine consultants from a background that was linked with oncology, rather than the traditional style of hospice medical director post. Palliative medicine specialist William O'Neil argued against mandatory attachment to oncology for palliative medicine trainees, he envisaged such a relationship would mean the focus would be on oncology rather than broader medical problems. It was

proposed that oncologists should spend some time in palliative medicine because the majority of patients treated by oncologists were not referred to palliative care (Bennett et al., 1996). This implies that there was some resistance from oncologists to palliative care because they did not tend to use their services. Finally, a general observation was that wider political structures were operating to make cancer and palliative care services more cohesive but this also caused tension (Association of Cancer Physicians, 1994; Bennett et al., 1996; Department of Health, 1995). On a critical note, the paper by Bennett et al (1996) would have been even more enlightening if individuals from a greater range of backgrounds had been involved. For example, general practitioners could have provided a community viewpoint and informed oncology and palliative medicine trainees about general practice work.

One of the greatest challenges must have been how to replicate the philosophy of the pioneers to enable everyone involved in this work to practise holistic care. It is important to emphasise that those who had not chosen to do end of life care were now being expected to provide it. Some might not have had a desire to care for the terminally ill, which would make it difficult to carry out this work along the lines of the holistic philosophy of the pioneers. Kearney (1992) flagged this up as a concern and was anxious that practices did not succumb to the medical model as discussed. The policy recognized this to some extent because services were said to be uneven and not as good as they should be, support at home was poorly coordinated and too many patients continued to experience poor psychological and social support (Department of Health, 2000).

On a final note, the overall impression that was made of this general picture was that whilst notable achievements had been made during the period of my study there was still much to be done. The key problem detected was that the United Kingdom had fewer oncologists than other European countries, the increase in funding meant that by 1999 there were '305 clinical oncologists', '110 medical oncologists' and '94 palliative care physicians' (1999 Consultant numbers, Department of Health Workforce Census, September 1999, cited by the Department of Health, 2000, p.74). Yet there were still inequalities across the country because of difficulties accessing radiotherapy and the government promised more investment

(Department of Health, 2000). A review of developments at the end point of my study found that there had been improvements in service delivery, but progress remained patchy and there was still much to achieve (Commission for Health Improvement, 2001).

1.4 Summary

In this chapter I explored the evolution of cancer and palliative care services in the light of wider social and professional issues that impacted on developments. This broad literature review helped frame some of my research questions. For example, accounts of the history of hospice development influenced the construction of questions about philosophy of care and practice (see chapter 3). It made me contemplate how this type of work might have impacted on the lives of participants and how their lives could have affected this cancer and palliative care work. It also highlighted that the lack of political and professional interest meant that different paths were taken, which led to a heterogeneous cancer and palliative care landscape. During the period 1976-2000 there were great achievements some of which had their origins in the modern hospice movement and its underpinning philosophy, yet there were also tensions mainly about the direction of services and inequalities in accessibility. It appears that many of these issues arose because there was no central planning in the first instance. In this context, local activists developed services often using whatever support they could find in the area. Cancer and palliative care services have a rich history, this has at times been due to differing perspectives between the voluntary and State sectors. One reason for this was probably because local needs were not homogenous, therefore facilities had developed in accordance with what local people perceived was needed for their communities. The National Health Service 'services' were not as heterogeneous because they needed to work within national strategy in order to take into account the general health of the population. One of the greatest challenges was that so many varied services evolved in the relevant time period. The first palliative care policy created in 1987 called for all hospitals to make provision for palliative care, but it came 20 years after grass root activities had first become established at St Christopher's (Higginson, 1993). I indicated that in 1987 the Association of Cancer Physicians put forward proposals for the development of cancer medicine at district level; further

guidance came in 1995 and then in 2000 with the National Health Service Cancer Plan (Department of Health, 1995; Department of Health, 2000; McIlmurray, 1987). Yet this also came 10 years after some activists had formulated local strategies (McIlmurray, Gorst, Holdcroft, 1986). Gradually it has been seen that interest from professionals and the government gathered momentum and strategy emerged. However, there were challenges because of relationships between the statutory and voluntary services and amongst the charities themselves. These services were all contributing in different ways to the provision of care; at different periods they influenced each other and were influenced by one and other. On the one hand this brought about a level of cohesiveness, whilst at the same time it created the tension described.

In this chapter I have reported my general findings on cancer and palliative care service developments, and it is against this wider context of national developments that I studied one local area in order to see how these broader issues were played out in one place. There are no studies on how cancer *and* palliative care services (together) have developed at the local level, and this study is an attempt to fill that gap. In the next chapter I explore the underpinning methodology of the study.

¹ I searched key electronic databases - ASSIA, IBSS, Soc Index with Full Text, CINAHL, EMBASE (Ovid), MEDLINE, Psyc INFO, BIOSIS and Web of Knowledge. I used the search terms 'history of the modern hospice movement' in order to find primary research. A total of 59 papers or books were identified. I only used papers, which were published in the English language. I then assessed the papers objectively to determine whether they were relevant to the history of the modern hospice movement. I decided to include studies using qualitative, quantitative or mixed methods. I applied the inclusion and exclusion criteria to the papers by reading the titles and abstracts. 51 papers were excluded because they were not in English or they only referred to secondary sources or were duplicates. The remaining 8 were assessed in full. Out of these three related to studies involving primary research and two of them were carried out in the United States. The only primary research looking at how services evolved in Britain was 'A bit of Heaven For The Few?' (Clark et al., 2005). Therefore it was necessary to carry out some purposive hand searches to identify other relevant information relating to the development of cancer and palliative care services. I also examined a number of papers on hospice development that had been recommended when I undertook the Postgraduate Certificate in Health Research (End of Life Care) in the Faculty of Health and Medicine at Lancaster University. I analysed some data held by The Hospice History Programme (2010) so that I could compare developments around the United Kingdom. I also used oral history from the Witness Seminar on Palliative Medicine in the UK c. 1970-2010 (Overy and Tansey, 2012).

CHAPTER 2

METHODOLOGY

2.1 Introduction

This chapter concentrates on epistemological issues that underpinned the study's hybrid design and its grounding in a coherent qualitative research framework. It explores how traditional forms of knowledge and history were shaped by wider social issues, which advantaged quantitative evidence based research. Similarly, documentary evidence was historically considered more authoritative than oral sources and some of the reasons for this are discussed. It analyses how this changed in time, as oral history redressed the balance and gave those who were less socially powerful a central place in which to create their own history (Thompson, 1988). In addition, it examines some of the challenges initiated by the sociology of scientific knowledge and investigates how controversies about different forms of research were resolved and influenced medical history research. For example, it investigates how critical interpretations of science demonstrated that science/medicine have socially constructed dimensions, and this went some way to increasing the respectability of qualitative research generally (Lane, 1995; Nettleton, 1995; Pinch and Bijker, 1984). It also explores ways in which oral history methodology resonates with social constructionism. In addition, it examines some of the criticisms of social constructionism.

I chose a qualitative methodology for my study because I wanted to explore experiences that would reveal how individuals developed cancer and palliative care services. Furthermore, I wanted to examine how care was provided at the end of life. Through interpretation I hoped to make connections between these developments and social, individual, political, historical and professional factors to uncover what impact they had on local developments. I anticipated that these links would enable me to place the research findings about service development in the

wider context of cancer and palliative care issues and increase understandings about the change in the course of time. Ultimately, I hoped that the methodology would complement the method in order to address the study's aims and answer the overarching research question - 'How were cancer and palliative care services developed in Lancaster 1976-2000?'

2.2 Underpinning epistemology

I start by exploring the methodology at the foundation of this study and which complemented the oral history method. Portelli (2006) argues that oral history is a qualitative approach because it focuses on individual experiences and can link these phenomena to broader historical and social circumstances, yet the underlying theory is sometimes not so apparent (see chapter 3). This thesis argues that the epistemology underpinning my study benefited from some elements of the social constructionism approach. Furthermore, as a result of shared epistemological constructs between the methodology and method, social constructionism offered a fruitful theoretical basis for understanding more about the oral accounts. My justification for making this claim is that constructionism looks for answers as to how knowledge is formed in the social world; similarly oral history interprets the meaning individuals attach to significant experiences and the social relations within particular places (Mallinson et al., 2003). For example, Watson and Woods (2005) used oral history to explore the development of wheelchair seating. By focusing on accounts they were able to link experiences in the wider context, to show how the social lives of people with learning and physical disabilities were transformed by changes in the design and use of wheelchairs. Some individuals were able to leave the institution and access the outdoor world for the first time in their lives. Thompson (1988) argues that oral history is socially formed '...inevitably pursued in a social context...' (Thompson, 1988, p.viii), and there is a shared understanding that social processes are integral to knowledge formation (Nicolson and McLaughlin, 1987).

There are some qualifications because the interpretation of experiences will vary between time and place, my study focused on the period 1976-2000 so experiences needed to be related to

the historical circumstances for that time (Nettleton, 1995). It was also located in a specific context, one small city in the North West of England. Later in this chapter I will suggest how the work of Pinch and Bijker (1984) could be applied to an oral history of the development of cancer and palliative care services because of other shared key features. I will now look at the imbalance in power between different forms of research methodology.

2.3 Unequal methodology

Historically qualitative research methodology (including oral history) occupied an inferior position in the evidence-based hierarchy, and this section offers some suggestions as to why this was the case. Three key issues were identified that linked this imbalance with unequal social factors and conventional forms of history. Take the documentary method which was one way to produce history, conventionally it focused on the lives of those who were socially influential and in doing so it produced an exclusive form of history (Winslow, 2009). Second, since the lives of 'ordinary' individuals were neglected by 'grand' history they have tended not to feature in official documents (Gardini, 2012). Marginalized groups such as the proletariat, women, and disabled children to take just some examples were therefore deprived of producing history (Thompson, 1988; Watson et al., 1999). Third, these historical and social inequities ensured that documentary sources such as official records, reports and newspapers ranked higher for historians in the evidential hierarchy than the oral method (Mallinson et al., 2003). Yet if historians only used documents which related to those from similar backgrounds, the work would be narrowly focused. Such an approach also suggests that the mind which privileges documentary sources perceives other methods such as the interview through a sceptical optic because it deviates from precepts of the documentary method. By way of illustration, Hobsbawm (2009) argues that one cannot rely on memory for a reliable chronology of what 'actually' happened in the past, and written records have more authority. Similarly, Taylor (no date cited by Davis, 2010) accepted documents as providing a more 'truthful' history. However, from a critical perspective the pursuit of a singular truth waiting to be discovered in documentary sources fails to uncover other forms of history and explanations, even where there might be alternatives. It appears that those who advantaged the documentary

method positioned the oral source inferiorly in the evidential hierarchy, thus affording it less power. Nevertheless, in time oral history became an authoritative source of history for ‘all walks of life,’ and four significant innovations were detected as shaping this change. First, moves towards developing oral history research began to surface in the United States of America around 1948 when the International Oral History Movement was created, and Allan Nevins of Columbia University began to use this approach (Fingerroos and Haanpaa, 2012). Second, by the 1960s the approach had spread to the United Kingdom; oral historians there recorded the history of those in less socially influential positions within communities. Yet Nevins had actually interviewed influential, white males possibly because he understood that elites would be more likely to influence his work by making it respectable. Third, oral history in the States eventually expanded to include less powerful people. Work that emanated from the University of Chicago such as that of Studs Terkel, included Americans from ‘all walks of life’, marginal groups as well as influential that chronicled the profound and often tumultuous changes taking place in twentieth century America (Chicago History Museum, 2002).

Fourth, throughout the 1960s and 1970s oral historians in the United Kingdom expanded the research base that recorded the lives of workers, women and children to reveal an interesting form of history which had not previously been considered valuable. For example, Roberts (1984) observed that the ordinary lives of working class women revealed that very few had achieved any public prominence, yet they played critical economic roles within the family. They were remarkably efficient and were able to manage budgets, feed and clothe the whole family and keep them clean. Furthermore, Roberts (2000) found that by studying individual uniqueness it was possible to understand more about particular viewpoints. Similarly in oral history work that explored Cubans’ life stories Dore (2012) found that life for some was not particularly long, unhappy or full of great events. Yet the oral accounts uncovered an interesting history of differing perspectives on life and demonstrated how they were connected to wider political mechanisms within the community. These illustrations are relevant to addressing inequality/inequity in research methodology because by focusing on those who were less influential, oral history challenged perceptions that did not see oral accounts of ‘everyday life’ as valuable forms of history and made them interesting/important. Moreover, as Thompson (1988) observes - oral history is ‘...perfectly compatible with scholarly

standards' (Thompson, 1988, p.2). In 1983 the National Sound Archive was created and oral evidence had in the course of time become a respectable source in academic research (British Library, no date). In addition the Millennium Memory Bank archive produced a cross-section of living memory in communities around the country, and there has been an upsurge of enthusiasm for the method in scholarship (Gallwey, 2013). In time, by recording the lives of first-hand accounts of an enormous variety of narrators, oral history has helped democratize history (History Matters, 2012).

Nonetheless, two key issues were detected as being important in treating oral history and documentary sources from a critical perspective. First, it is important to appreciate what oral history is able to capture, it is not the 'actual' event but an interpretation of a past time and place that is reconstructed in the present (Fingerroos and Haanpaa, 2012). Chagas (2012) found that the scenario reported by the oral history interview in journalism is not 'the event' but a report of the occurrence. Merchant (2013) puts it another way by explaining how stories told by scientists about their childhood do not tell us why they became scientists, they tell us how they viewed themselves when giving their accounts. This needs some qualification since Merchant's approach differed to mine because he concentrated on deconstructing the narrative in order to ascertain how individuals composed stories. Nonetheless, memories as well as formal interpretations of history are partial because they are fluid, created in the past and shaped by the present (Craggs and King, 2013). This has led some like Liljestrom to urge caution because one can be left with an incomplete understanding of the phenomena under study (Dore, 2012). However, if we consider the situation that might arise if individuals were actually present at an event, they could produce various contemporaneous accounts because each person would interpret phenomena differently (Goldenberg, 2005).

Second, similar critical observations could be leveled against documents because they are not the 'existing' eventuality. They are a written construction of the individual or aggregated social perception of facts and are exposed to social pressures from the context in which they were obtained (Thompson, 1988). Even documents that are considered to be a 'contemporaneous record' such as minutes of meetings and letters are not 'the event', but are

subject to the processing and interpretation of the maker. Moreover, archived records do not come to be available by accident; there is a social purpose behind their creation and subsequent preservation. Therefore Hobsbawm's viewpoint needs to be treated with a level of caution because it assumes that documents are rational, and this renders them more 'truthful' than other sources. That being said, both approaches have their merits when used in a critical way because they have the propensity to reveal a past and increase our knowledge of events. In an attempt to shed some further light on possible reasons for such controversy between these approaches to the form of history I will explore traditional perceptions of science. It should then be possible to critically examine why a methodology is considered more or less scientific and what problems might arise.

Conventionally science discovers knowledge *a priori*; scientists are seen as '...disinterested agents in pursuit of truth' (Abraham, 1994, p.717; Alderson, 1998; Sackett et al., 1996). Furthermore, in this field enclosed by unchangeable boundaries '...scientific beliefs stand or fall in the light of the evidence' (Goldenberg, 2005, p.2622) because there is but one method to follow, deviation from which will result in the failure to produce scientific evidence (Chagas, 2012).

When the historical developments of scientific knowledge were compared with those of written forms of history three key links emerged. First, there were similarities in relation to the hierarchical differences described between quantitative and qualitative methodology generally. For example, quantitative methodology and documentary sources were considered superior to qualitative and oral approaches. Second, the mind that advantaged the documentary method placed great importance on the text and perceived it as the only reliable source of history. Any deviation from the documentary method such as 'the interview' was perceived as less respectable/scientific in its generation of evidence. This was similar to the perception that the scientific method was the only way of producing scientific knowledge. Third, both the scientific method and documentary sources were powerful and seen as rational (Taylor cited by Thompson, 1988, p.53). Such assumptions were problematic because they did not question why documents were produced or whether there might be other versions. Carter Hett (1996)

critically underscores that whilst Taylor championed the documentary method, it was not uncommon for him to offer judgment on the past with one eye firmly on the present. Yet what happened at a particular time cannot be applied to later periods because knowledge ‘...is the production of a particular time and place...it embodies and expresses the character of the social circumstances under which it arose – the priorities, interests and taken-for-granted assumptions of the relevant actors’ (Nicolson and McLaughlin, 1987, p.116). In short, those conducting research underpinned by qualitative methodology were in a weaker position than researchers undertaking conventional work, and the burden was on them to demonstrate that there was more than one way of producing scientific knowledge (Nicolson and McLaughlin, 1988). I will now move on to examine how this was achieved.

2.4 Critical examination

The purpose of this section is to explore some of the challenges that were aimed at conventional approaches to the production of knowledge in order to increase the authority of qualitative research, and show that there were differing ways. Historical perspectives of science began to be critically analysed by sociologists developing the Sociology of Science, as they wanted to create a body of knowledge for their own discipline to make it respectable (Whitley, 1972). Initially studies were positivistic and followed a similar approach to the natural sciences because they were already respected, and sociologists hoped to gain similar prestige (van der Pijl, 2009). Nicholson and McLaughlin (1987) argue that this was problematic because it was based on the theory that only physical matter was ‘real’, and sociologists were not open to other approaches. They were merely a vassal state of the natural sciences passively accepting that science and scientists were rational. It is possible that it was considered an approach that would most likely enable sociologists to work collaboratively with scientists. Scientists would probably have been less likely to let sociologists study them if they did not consider they would follow an approach that resembled their own. Similarly, at the Witness Seminar on the history of palliative medicine Clark explained that palliative medicine specialists had been very receptive to the engagement of social scientists, and he suspected that this was rather different to other specialties in medicine (Overy and Tansey,

2012). Nevertheless, initially the focus was on how scientists came to be scientists and what materialistic rewards they received rather than questioning what they developed, or how they produced artefacts (Whitley, 1972). If the approach was applied to a study such as this, it might be preoccupied with the producers of cancer and palliative care services that focused on physical problems. It would take little if any account of facilities that were created to address emotional or social issues. Furthermore, it would not explore ideas on how and why services developed as they did. Yet ignoring the cognitive aspect of clinician's activity infers that it is non-problematic. All ideas are seen to be the same, social processes are assumed to have no bearing on what is discovered and individuals are considered rational. There is 'but one way' of understanding the world, every scientist knows the method and application of the linear approach produces scientific knowledge. Under such a theory the focus would continue to be on physical rather than emotional needs. Moreover, a quantitative epistemology would be considered superior because of its materialistic focus, and any deviation from convention would produce knowledge perceived to be non-scientific.

If the ideology of 'black boxism' (Whitley, 1972, p.63) were applied hypothetically in this research it would also be restricted to the currently observable inputs to and outputs from the services. So, the physical structures and buildings could be the outputs or even the physical symptoms of having cancer. The inputs might include the number of individuals providing services or physical care. It would not be an adequate method for exploring how social, cognitive, political, economic or cultural factors impacted on the services because any study of the internal processes would be excluded. Once again, the difficulty would be that the focus remains on material or physical symptoms rather than psychological, social or spiritual problems.

An alternative approach might be a 'translucent box' sociology of science because such an approach posits a particular mechanism of processes which transforms inputs into outputs. It would seek to answer the question '...how do social and cognitive factors interact to produce knowledge and what effect do different forms of scientific knowledge have on society?' (Whitley, 1972, p. 63). Such an approach acknowledges scientists' irrationality and can be

used to study what they do and how they make decisions in the production of knowledge, therefore it should be more useful. The theory might provide a way of opening the black box to reveal something of how local cancer policy/practice was made, but in order to gain as much from it as possible it would require the researcher to 'observe' the services developing. That would not be possible because the study is historical. It might offer an opportunity of unlocking the black box of interview accounts in an attempt to explore the mechanism of processes that converted inputs to outputs. The interpretative explanation indicates why the event occurred in terms of a mechanism that produced it. It might examine the participant's philosophy, practices and social connections and how they influenced the services. There is a need to '...go beyond the immediately observable to conjecture boldly about possible reasons for phenomena if we are to know more about the world' (Whitley, 1972, p.66). The approach would explore how social and cognitive factors impacted on practice and what affect services had on society. Yet this sociology of science would be too restrictive for understanding the impact of wider cultural, psychological, political and economic factors on the experiences of developing cancer and palliative care services.

The work of Pinch and Bijker (1984) is examined next in order to explore how controversies about whether knowledge was rational or socially constructed were resolved, and how this influenced medical history research. Whilst not a recent paper this is a classic study which has retained its usefulness; Pinch and Bijker's work was used as an instrument to increase understandings of the oral history accounts. I indicate how some of the theoretical concepts could apply to my study to push the boundaries generated by oral history. There were two key ways identified in which work from constructionist sociology opens our minds to differing ways of generating scientific evidence. First, the methodology challenges rationality by acknowledging that science/technological artefacts do not arise through linear (or one dimensional) processes. It demonstrates that observations are coloured by background beliefs and scientists filter input from phenomena according to their equipment, skills and priorities as Nicolson and McLaughlin (1988) found in their work about multiple sclerosis. The analysis of debates about whether the pathogenesis of Multiple Sclerosis was vascular or autoimmune had occurred between a powerful social group (immunology/neurology) and a weak and marginal one (hyperbaric medicine). The study highlights that all the actors had investments in

particular procedures and forms of expertise. It argues that the means by which competing statements about the real world were assessed was a social one, involving power, authority and status. Different observers of phenomena produced different conceptions of whatever was under study because modes of observation and the points from which observation takes place differ. Furthermore, the processes whereby input from the non-social world (in this study that would be the tangible cancer support facilities) was generated and incorporated into scientific knowledge (or practices) were selective ones. In addition, input from phenomena under study was filtered according to equipment, skills and priorities of the observer. That input fell not on a blank slate but upon a set of previously existing beliefs about the world, therefore we understand the unknown in the light of what we know – which has its roots in training and prior socialization. Social constructionism does not maintain that science or medicine are irrational, rather it is argued that scientific rationality is context-bound. Watson et al (1999) challenged the rationality of the concept of a disabled child because children in the study were able to demonstrate that they formed part of a heterogeneous group. The researchers identified a range of ways in which meaning and values were contested, or reinforced in daily interactions and institutional practices. Although this was not oral history or a work using Pinch and Bijker (1984), the point I am trying to make is that it was similar because like Pinch and Bijker it challenged the rationality of a ‘taken for granted’ phenomenon. Watson et al (1999) found that the children in their study were a varied group; they were not all the same because they had a disability. Analogously, oral history also challenges rationality because it looks for a range of perspectives rather than ‘one view’ (Walmsley and Atkinson, 2000). In doing so it questions the social, political and/or cultural factors shaping any given set of phenomena.

Second, social constructionism sees ‘reality’ as phenomena the actors construct and in which no single construction is more correct/real than another and what is regarded as true, valued or expected in one social system may not be so in another. When investigating the causes of beliefs/experiences the researcher should be impartial to the ‘truth’ or ‘falsity’ of the viewpoints, and such beliefs should be explained symmetrically. In other words, differing explanations should not be sought for what is taken to be a scientific truth and a scientific falsehood. Within such a programme all knowledge and knowledge claims are to be treated as

being socially constructed, explanations for the genesis, acceptance and rejection of knowledge claims are sought in the social world.

If this is applied in a theoretical way here, then when assessing the positive and negative experiences of developing cancer and palliative care services perspectives must be explained symmetrically. The researcher takes a neutral stance and provides a balanced reconstruction of accounts. There might be discrepancies between oral and written accounts; one is not necessarily more reliable than another because they might represent different standpoints (Thompson, 1988). By way of illustration, Dore (2012) found Cubans' life stories emphasized both the pleasures and aggravations of life in Cuba; this should not be surprising because by analyzing accounts in a non-judgmental way (symmetrically) it was possible to uncover a range of views. For example, some participants had positive experiences about certain aspects of life yet others had negative encounters of similar circumstances.

The Empirical Programme of Relativism (EPOR) developed in the Sociology of Scientific Knowledge focuses on the empirical study of contemporary scientific developments and controversies; it attempts to understand the content of the natural sciences in terms of social construction. It might concentrate on certainty and uncertainty in scientific debate, mathematical disputes or the evaluation of medicine safety because they are all areas where contentions arise (Abraham, 1994; Bloor, 1978; Pinch, 1981). I will explore whether it could be useful in a retrospective study exploring cancer and palliative care services. It might have some uses but it would be different because my study is historical, and there would be no opportunity to gather data as services developed. Pinch and Bijker (1984) recognized that there were three key stages to the development of scientific findings. In the first stage of the EPOR interpretative flexibility of scientific findings is displayed. Applying this here would be like finding that cancer and palliative care services have different meanings for different actors, and practices like viewpoints/actors are flexible because of differing forms of rationality. In short, there will be a need to show that different interpretations of the cancer and palliative care services are available.

In the second stage of the EPOR flexibility disappears because consensus emerges to say what the 'truth' is as social mechanisms limit interpretative flexibility and terminate controversy. This might link social and professional peer pressure to what is considered an acceptable service. The third stage links closure mechanisms to the wider social-cultural milieu, this might relate to practice and policy being shaped by external social, political and professional factors. These stages become less malleable in the course of time because while science is characterized by many areas of certainty, there are areas where controversy rages and the certainty of knowledge seems far from being assured (Pinch, 1981). For example, the 'Core-Set' comprises a group of scientists who in a controversy are actively involved in experimentation, observation, or make contributions to the theory of the phenomenon. Therefore they have an effect on the outcome of the controversy as they produce knowledge. It is activity within the confines of the 'Core-Set' where '...reality is up for grabs...' (Pinch, 1981, p.152) that is characterized by an aura of uncertainty, as it is here where knowledge is socially constituted (see later). If applied to cancer and palliative care services the focus would be on developments and controversy with the proponents acting as the Core-Set. This needs qualifying because in my study it would not be possible to monitor consensus by observing the Core-Set doing their work. However, oral history accounts could be examined to see how controversy was dealt with and how consensus was reached and socially negotiated.

Pinch and Bijker (1984) were also able to demonstrate through the Social Construction of Technology (SCOT) that technology like science is also socially constituted. The SCOT challenges rationality and adopts a relativist perspective to show how things could have been otherwise. The rational mind would not look for alternatives as Chagas (2012) demonstrates in journalism; an event becomes newsworthy because journalists usually follow a linear process in the reconstruction. However, rather than taking a technological artefact as the starting point and assuming that it is evidence of its success (by applying a linear model), a constructivist account would conclude that the successful stages in the development are probably not the only ones. The application here would be different because there is no single tangible artefact; rather an intangible service with tangible assets such as buildings. A detailed study of developments in the course of time would prove more fruitful because it might reveal that routes followed were not the only ones that could have been taken. There is a need to look at

wider factors because then it becomes apparent what impact they might have had on how and why services developed as they did.

My study offers one way of challenging assumptions from a linear model because it explored the 'actual' situation between 1976 and 2000, rather than taking the end product of services as evidence of their success. If a multi-directional model is adopted it should be possible to question why some services, ideas or roles died yet others survived because oral history reconstructs from a multitude of differing accounts (Walmsley and Atkinson, 2000). It is necessary to consider the problems and solutions presented by the cancer and palliative care services at particular moments in order to illuminate the 'selection part' of the developmental process (of what lives and dies). This should bring out more clearly the interpretative flexibility of cancer and palliative care services. It appears that as a result of stabilization the process (and decision-making) that went into creating an artefact (or knowledge, practice or service) is no longer critically perceived or questioned. Instead the 'existence' of phenomena are in themselves taken as evidence of success. The artefact (or service) is then assumed to be rational because stabilization results in it becoming 'taken for granted' like tacit knowledge. Now we are left with a potentially problematic situation because the danger in accepting that something is rational means that one fails to question that there might be other explanations as to why something is as it is.

In deciding which problems are relevant the groups and meaning they give to the artefact play a crucial role, because a problem is only defined as such when there is a group for which it constitutes a dilemma. The relevant group here would be those involved in hospice and cancer support work, but it is necessary to determine whether there might be a broader group including perhaps those with dissenting views (Pinch and Bijker, 1984). There is a need to find out what problem the group has with the artefact. It might be possible to 'observe' this through interpreting the meaning behind experiences of paths taken or abandoned in the accounts to increase understanding of how services developed. By uncovering the process of stabilization, the development of cancer and palliative care services would not be seen as an isolated event or existing in a vacuum. Moreover, a retrospective exploration would reveal

how facilities evolved in a 24 year period rather than taking the existence of services (or the end point of them) as evidence of success. In this section I have explained that oral history and social constructionism share similar perspectives of methodology, and I explored how social constructionism could be used to increase understandings of oral history accounts. Furthermore, the analysis has explored how through social constructionism knowledge is socially constituted, yet such an epistemology has created tension and the key controversies and ways in which these have been resolved are discussed next.

2.5 Scepticism

Although research such as that performed by Pinch and Bijker (1984) used social constructionism to demonstrate that all knowledge is socially constructed, the methodology is not without challenges and these have been criticized. This section will demonstrate that whilst there could potentially be problems if taken to the extreme, a moderate interpretation informs us that the physical world is not a problem to social constructionism. Therefore any scepticism needs to be treated with some caution. It also explores problems that can arise if medicine is assumed to be rational and it indicates how this might link to the history of cancer and palliative care services.

Historically, medical knowledge developed along an analogous path to science, it privileged a linear method and became increasingly concerned in laboratory science which had a materialist focus (Sturdy, 1992). These historical factors were identified as possibly impacting on conventional medical approaches because they focused on disease and perceived physical symptoms as being 'real' problems. There were two key issues indicating why this paradigm was particularly problematic for those with cancer. First, historically cancer services were organized around modalities of treatment for cancer disease and second, emotional support had not been taken into consideration (McIllmurray and Holdcroft, 1993). Once again, there was a pattern of emphasis on physical phenomena within medical knowledge and practices

were focused on treating disease. Consequently, emotional and spiritual issues were not seen or constructed as tangible problems.

When social constructionism has been used to analyse the construction of medical knowledge to reveal that it is socially negotiated in a similar way to science it has found criticism. For example, Bury (1986) criticizes social constructionism because it resists the assumption that knowledge is rational. It asserts that objects of medical science are not what they appear to be - stable realities of the human body and diseases are fabrications/inventions rather than discoveries. Only at the point when sufficient agreement is reached amongst scientists as to the 'reality' of a given finding carrying the necessary degree of authenticity can that reality be regarded as existing (Bury, 1986 citing Barnes, 1982). Barnes' work, along with that of David Bloor emanated from the Strong Programme of the Sociology of Knowledge developed by the Edinburgh School in the 1970s (Nicolson and McLaughlin, 1988). The suggestion by Bury appears to be that physical phenomena exist, regardless of whether or not they have been socially constructed. Moreover, that *per se* undermines the theory that all knowledge including medical knowledge is socially constituted, because if it were then it would not be possible for 'real' objects to exist unless (and until) they had been socially negotiated.

However, a key factor identified as to why it is possible for the physical world to exist independently of social constructions is that it could exist as physical phenomena, but not in the form of 'knowledge' as such because scientific knowledge that comes from the physical world is socially constituted (Pinch and Bijker, 1984). Nonetheless, it is important not to lose sight of the connection between knowledge and the real world because knowledge is related to activity, which consists precisely in men and women attempting to manipulate and control the real world. Knowledge is found useful because the world is as it is, and it is to that extent a function of what is real and not the pure product of imagination. Similarly, knowledge arises out of encounters with reality and is continuously subject to feedback-correction from these encounters (Barnes, 1977, cited by Nicolson and McLaughlin, 1987). The interpretation I made can be illustrated by taking a cake as an example; if social constructionism is abstractly applied to it we need to ask what the social construct is. For Barnes the 'cake' does not exist

until a measure of agreement is achieved amongst bakers as to the reality of the given phenomena, that is – the cake passes the test in relation to the authenticity expected because only then can the cake be regarded as existing. The ingredients existed as real objects, but it is only through social construction that the cake becomes acceptable as a cake. Therefore recognition of the physical properties of natural objects poses no problem for social constructionism (Nicolson and McLaughlin, 1987).

There are further problems when the rationality of medicine is questioned because it becomes apparent that there is no ‘one way’, rather there are a range of perspectives as a result of uncertainties. For example, this relates to whether drugs should become licensed for prescription; ‘These deep and extensive...uncertainties in drug testing partly account for the fact that scientists...can review the same data about the safety of a medicine and reach entirely contradictory regulatory decisions...’ (Abraham, 1997, p.161). Similarly, Lane (1995) observes that it is unlikely the debate about safety relating to location in obstetrics will be resolved satisfactorily because the definition of risk is a contested terrain. There is also a range of opinion about different conceptions of diseases such as Multiple Sclerosis because ‘...modes of observation, and the points from which observation takes place, differ’ (Nicolson and McLaughlin, 1988, p.234). Bury’s argument is therefore problematic because he assumes medicine is rational, which in turn leads to an expectation that one treatment is better than another and misses the opportunity to question whether there might be alternative paths.

The key point for our learning here is that by questioning the rationality of cancer medicine, it became apparent that physical symptoms and mechanistic practices were not the only problems or ways of providing care. There were also emotional and psychosocial difficulties which were equally as ‘real’ to those who experienced them (Addington-Hall et al., 1993; McIlmurray, Gorst, Holdcroft, 1986). Therefore, when a relativist perspective is practised there is a commitment to accepting that each doctor might have an opinion because it acknowledges that there are a range of viewpoints, and one might not necessarily be better than another (Lane, 1995). In relation to individuals with cancer, a relativist perspective would acknowledge that there might be a range of problems including emotional, social and spiritual

as well as physical. Therefore through careful evaluation of the evidence Bury's scepticism should be treated with caution.

This section has demonstrated that the problem of assuming medicine is rational is it leads to a presumption that there is one way/problem/explanation and misses the opportunity to question whether there might be alternative answers or approaches (see chapters 4-6). Moreover, the difficulty of assuming conventional cancer medicine was rational was that the focus was on cancer as a disease, and this approach was not initially questioned therefore only physical problems were deemed real. In the next section I examine other ways in which the methodology and method complement each other.

2.6 Transfer of theory

There were some additional ways identified in which oral history methodology resonates with social constructionism. First, oral history epistemology understands that 'Reality is complex and many-sided...it allows original multiplicity of standpoints to be created...' (Thompson, 1988, p.5). Second, it is democratizing (like relativism) because different representations of history are equally important; all of them have to be taken into account in the interpretation of meaning (Fingerroos and Haanpaa, 2012; Mallinson et al., 2003). The *sine qua non* of qualitative methodology is that researchers have a commitment to seeing through the eyes of participants, and accounts taken from a wide group provide a fuller picture because they challenge rationality and seek alternatives (Bailey et al., 2002; Lars-Christer, 1997; Thomas et al., 2009). I have explained that I wanted to uncover *inter alia* how cancer and palliative care services evolved, how individuals were cared for at the end of life, how complementary services were developed in a culture that stigmatized death, dying and cancer, how these services changed in time and what caused that change (see Introduction). Oral history can shed light on how and why people behave because it harnesses the subjective nature of behaviour, and accounts can be considered collectively to reveal the socio-cultural contexts in which

health decisions are made (Carter and Henderson, 2005; Clark, 1997; Robson, 2002; Soothill et al., 2001b).

I analysed various oral history studies in an attempt to explore the approaches to methodology. The theory underpinning oral history about learning disability carried out by Walmsley and Atkinson (2000) was identified as resonating with social constructionism. By way of illustration, when interviews from a Mental Welfare Officer and a patient were juxtaposed they provided different ‘realities’ of learning disability in the ‘same’ community, and at the same period. Yet the Welfare Officer’s construction was of a benign institution but the patient’s was of a cruel, oppressive, uncompassionate environment. It is not a case of one account being better than another because they need to be considered symmetrically; they are additional resources to add to the debate about history (Pinch and Bijker, 1984). Walmsley and Atkinson (2000) situated and contextualized accounts because they uncovered language used in statutes that described disabled individuals as ‘uneducable’ and ‘idiot’ and thus demonstrated how legislation impacted to restrict viewpoints. Furthermore, unless a person was diagnosed with one of these labels they could not access finances from the health budget to pay for services. Gender also impacted on decisions taken because only the father was required to consent to the hospital admission of a person with disabilities. In a social context there were linear consequences of the narrow attitudes, individuals were excluded from their communities and hidden in the home or institution as a result of having learning disabilities.

Withers (2012) drew on critical theory to enact a ‘compassionate historiography’ because she found oral histories contained laughter and crying and offered a potentially wider range of emotional evidence than written sources. The study used archived material and interviews with the UK Women’s Liberation Movement, it was possible to create insights about the emotional work because the sources provided an opportunity to analyse the emotional impact of participating in the organization. My study was similar as oral history captures emotions by asking individuals what happened as well as how they ‘felt’ about it (Withers, 2012) (see chapter 5). However, it differed because I drew on theory from constructionism to increase understandings of oral accounts, and I used thematic analysis to analyse data (see chapter 3).

All of this work suggests that relativism is ubiquitous in oral history because it provides a thread throughout data generation and analysis. Also in the interpretative stage it aims to increase understandings about the meaning of significant events to individuals. What is important is not to ascertain what 'exactly' happened but to reveal what individuals want to reveal, and to consider how they compose their memories in the present (Peniston-Bird, 2012). Work by Peniston-Bird (2012) on the Home Guard reminds us of the need to remain attentive towards the 'collective story' because individuals compose memories in such a way so as to be able to live with them and through cultural conventions. Yet we should be alert to the possibility that there might be differing accounts. For example, the war has often been remembered as a time when everyone pulled together for the good of the war effort. Academics have not been able to find another version beyond a construction, which offers an appealing interpretation of national character and unity of the meaning of Britain's past (Peniston-Bird, 2012).

Clark et al (2005) used oral history accounts from hospice proponents telling in the main a positive story about the hospice movement. Rather than analysing the way individuals told their story and deconstructing the narrative accounts were arranged thematically (see chapter 1). Any criticism about hospice developments came from the participants' constructions rather than the researchers. Although the researchers selected the themes for reconstruction, and some respondents were critical of the way in which developments took place. Similarly, I have explained that work interpreting memoirs written by key actors who developed cancer services underscored how the multiple realities were squeezed into an 'official' version, 'No hidden skeletons were revealed...' (Soothill and Thomas, 1998, p.69) (see chapter 1). Therefore, the researchers did not find any fractures in the collective construction (Peniston-Bird, 2012). Nonetheless examining the way people told their history revealed defensiveness as a shield against possible challenge towards practice or behaviour that did not conform to conventions (Soothill and Thomas, 1998). The researcher is obliged to take account of the subjectivity of the participant in producing scientific truth because what people believe in their reminiscences contains more information than what actually happened (Portelli, 2002 cited by Fingerroos and Haanpaa, 2012).

In summary, four important features have been identified which show that social constructionism has much to offer oral history. First, it is of the perspective that all knowledge is socially negotiated. Second, it challenges rationality, third it is underpinned by relativism and searches for alternative explanations/ways/approaches. Fourth, it is non-judgmental. Remembered information is constructed, consequently what is produced in an oral history of the development of cancer and palliative care services is a reconstruction, which is located within areas of interpretative science because constructions are interpretive.

2.7 Summary

I will now summarize the key issues from the illustrations provided on methodology for cancer and palliative care services. I have indicated that the way in which conventional science developed created an unequal hierarchy in research methodology and health practices. Within the powerful medical paradigm the focus was on physical signs and symptoms of disease at the expense of psychosocial factors (Nettleton, 1995). It was problematic for those with cancer because such rationality missed an opportunity to see that from a broader perspective there were important psychological and social facets of ill health, which were just as real as physical ones (McIllmurray and Holdercroft, 1993). McIllmurray (1992b) argues that the psychosocial support services were inequitable and unequally distributed across the country, despite high levels of psychological morbidity experienced by patients. Similarly others have also argued that health inequalities are linked to unequal social circumstances and increased levels of morbidity and mortality (Black et al., 1980; Graham, 2004, Mallinson et al., 2003). My analysis of methodology has illuminated that constructionism questioned taken for granted assumptions and uncovered a different 'reality' in which to create knowledge. In the course of time the mind was opened to exploring beyond physical diseases, and patient's experiences of cancer services and their emotional needs became interesting areas for research (Soothill et al., 2001a; Soothill et al., 2001b).

In addition, I have suggested that one reason for initial tension in respect of the use of oral history might be found in the history of methodology generally, furthermore the documentary method was advantaged and followed similar theoretical/linear principles to conventional science. In the course of time constructionism critically evaluated science and demonstrated its socially constructed nature. This paved the way for qualitative research/oral history to gain respectability and become accepted scholarly methods of generating scientific knowledge. Constructionism and oral history share a similar theory of knowledge formation because they are critical of rationality and share relativist perspectives.

I have applied constructionism to my study in a theoretical way to show how it could increase understandings of oral accounts and therefore complement the method (see chapter 3). Furthermore, in the empirical chapters this theory is embodied in the reconstructions. I demonstrate the heuristic value of constructionism in identifying the social processes that had a bearing on knowledge. Exploring the links that can be drawn between the methodology and method will highlight the individual, historical, social, economic and political factors that shaped services. This was important because I wanted to uncover how cancer and palliative care services developed in one place at a particular time. Therefore I needed to reconstruct a story in the context of the time within which the services developed. In the empirical chapters I explore how the oral history approach, together with the underpinning epistemology described enabled me to do this. I focus on differing experiences in accounts and link these with historical and social mechanisms to reveal how they impacted on services (Mallinson et al., 2003) (see subsequent chapters). In addition I wanted to capture experiences of how care was provided at the end of life and how this and other developments changed in the course of time (see Introduction). I wanted to build on work by Clark et al (2005) and make a further contribution by uncovering developments in the local cancer and palliative care setting. There were a number of questions that arose in relation to answering the overarching question - 'How were cancer and palliative care services developed in Lancaster 1976-2000?' For example:

- How did individuals come to be involved in cancer and palliative care?

- What was the philosophy of care?
- Did participants feel part of something special?
- What links and bonds were forged between/across the organizations?
- What impact did charisma, routinization and bureaucracy have on developments?
- What were the changes and challenges in the course of time?

(See chapter 3 for more details of what I hoped to address).

In addition, I wanted to uncover accounts from a wider group than those involved in the study by Clark et al (2005) which focused on hospice champions and the work of Soothill and Thomas (1998), which involved individuals who set up the local cancer services. The latter work did not reveal any tension (see chapter 1). I hoped that the methodology and method would make connections that would reveal some of the challenges as well as the impact of broader historical, social, political, economic and professional structures on developments. The next chapter explores the oral history method and explains how it was supported where possible with documentary sources.

CHAPTER 3

METHOD

3.1 Introduction

The purpose of this study was to uncover how cancer and palliative care services developed in one place and how they changed over a particular period of time. This chapter describes the historical methods applied to generate data about these services for analysis and interpretation. It reports on how I used two key sets of material, oral history and documentary sources to address the aims of the study and to answer the overarching research question. In addition, it will specify and justify the design and choice of method. It will also show how the oral history complemented the methodology (see chapter 2). The strengths and challenges of oral history are appraised and I explain my reasoning for choosing the Lancaster area. This chapter also lays down some background context to local services, introduces the participants, and describes the recruitment procedure - taking into account research ethics/consent issues. It discusses snowball sampling and indicates how questions (in the interview schedule) were created. Finally, it describes thematic analysis/constant comparison similar to grounded theory that was used to analyse the data and reflects on the interview experience (Glaser and Strauss, 1967; Seymour et al., 2003; Seymour et al., 2004).

3.2 Method of data generation

My reason for combining oral history and documentary sources was because I wished to explore whether oral accounts would be supported by the material in the documents. I found however that they were not equally weighted, as interviews provided the majority of the useful primary data. Documents generated original and secondary data, helped to clarify dates and contextualize accounts because they uncovered political, historical, individual, social and cultural factors that impacted on policy and practice to create change; but in the main they were in a 'supporting role' to the rich material revealed in the oral histories.

3.2.1 Appraisal of oral history: strengths and challenges

There were three key justifications for using oral history. First, I explained in chapter 2 that oral history and social constructionism share similar epistemological constructs and have the potential to work together to increase understandings of accounts. I hoped these accounts would show how cancer and palliative care services developed in Lancaster (1976-2000). Second, I wanted to build on the tradition of collecting history about the lives of those who do not normally appear in the history books as well as those that do. By way of illustration, the views of doctors often feature but those of hospice volunteers do not, and in that sense my study follows a tradition of oral history work. Third, I also wanted to make connections between the accounts and social and historical factors in the community and broader arena, to demonstrate how they impacted on developments (Mallinson et al., 2003). Smith (2007) explains how classic community studies focused on a particular social institution in a community, such as Young and Willmott's 1957 study of the family in Bethnal Green and Bell and Newby (1971) on the interrelationship of social institutions. In 'Coal is our Life' conducted by Dennis, Henriques and Slaughter in 1956 the focus was on influences on employment, leisure and family in a single mining community.

This kind of work has the propensity to make links between daily life and social and historical factors in the wider context, to show what influence they had at that time and to examine these in depth in a single community situation. I have explained that Dore (2012) used oral history to uncover the lives of 'ordinary' people living in communist Cuba who were thought to be too afraid of talking to researchers about 'everyday life' (see chapter 2). Yet the method is advantageous because it enables individuals to tell their life story with considerable frankness. Dore (2012) found it was also possible to show that the pleasures and difficulties of life were shaped by broader economic, social and political structures. Roberts (2000) explored 'daily life' in a working-class community - Barrow and Lancaster c.1890-1914. In Roberts' archive there is an account from a woman about a day in her life when she was 12 years old, her mother had given birth but the baby had died, it looked, she said like a little doll wrapped in a sheet. The mother told this woman to have the day off from school and go to the shop for a soapbox in which to put the baby before taking it to the cemetery. She described how she cut the black lining out of her father's coat and lined the box to make it 'look better', then put the baby inside and walked to the cemetery. She gave it to the cemetery attendant who sent a

message to the mother that everything would be fine – meaning the baby would be buried in a public grave and the family would not have to pay for a funeral (Roberts, no date). The testimony was not analysed it was presented in a transcript, and it provided a sense of the way of life because it contextualized the account in time and place. It revealed that prevailing economic factors impacted to cause inequality because the family could not afford a funeral. The account also appears to indicate that there was a level of social/cultural understanding within the community, for instance by adhering to customs (sending the baby to the cemetery with a sibling) the baby was buried at the cemetery. It also provided a glimpse into growing up and into women's life in the North West, and in this case the frankness afforded to the daughter by involving her in bereavement. It is unlikely that this fascinating work relating accounts to the prevailing economic and social conditions features in conventional history.

Oral history has the potential to enrich our understanding of life in a particular period against the prevailing background of the day. Typically the method takes the accounts of 'ordinary' working class people so that we can learn about their lives (Thompson, 1988) (see chapter 2). Yet researchers have in the course of time studied a variety of social groups in order to uncover their experiences. Some have gone outside the oral history tradition of focusing on the weaker groups and have conducted interviews with those in authority. For example, Virginia Berridge interviewed elites about health services and argues that oral history should be used in this way, because it provides an insight into how influential individuals behave in creating health policy. Moreover, it can be difficult to uncover the decision making process in relation to health strategy that is forged by such groups, and oral history provides a way to address this (Berridge, 2010). I will now explore this approach in more detail in relation to hospice, cancer and palliative care.

3.2.2 Some approaches to oral history in hospice, cancer and palliative care

Having looked at the ideas and philosophy underpinning oral history this section reviews previous work that has employed this method in the study of hospice and cancer work. It starts out with an examination of the work of Clark, one of the pioneers in this area (see chapter 1). Clark (1990) explored the developments of Newark and District Hospice Aid 1987-90. Although it was not an oral history five key elements were detected as to why this work was important in relation to my topic: It was one of the first studies to evaluate hospice care in the

United Kingdom. Second, it highlighted the impressive achievements of volunteers who had created ‘something out of nothing’. Third, this work increased awareness of palliative care issues and fourth, it contextualized hospice work within prevailing social, economic and cultural mechanisms. Fifth, by focusing on a community type of study Clark was able to document its historical development and show how the commitment of local people coming together made the project a success (Clark, 1991; Clark, 1992a; Clark, 1992b; Clark and Neale, 1994; Ingleton et al., 1995; Ingleton, White and Clark, 1996).

There were number of themes identified by Clark and his co-authors, for example there was a general lack of knowledge about the processes which led to hospice and palliative care developments and little understanding of the factors that affected progress. Furthermore, there was historically little evidence of any guidance or overarching plan for the provision of such services within the National Health Service. Three issues were found to be important. First, there were policy and resource implications because local communities were likely to continue to make demands for hospice type care, despite official scepticism about proliferation. Second, models of care interacted with wider contextual factors involving national policy changes to raise questions about how services could be further developed. Third, shifts away from traditional in-patient models of care were likely to highlight divisions between lay and professional groups, in their perception of how services could be delivered in their communities.

Winslow and Clark (2005) carried out an oral history study of St Joseph’s Hospice, Hackney during the first 100 years of its existence (1905-2005). St Joseph’s Hospice was created by the Religious Sisters of Charity to serve a community in the East end of London that was characterized by a long history of material poverty and deprivation. It was also where Cicely Saunders began her early work with the terminally ill. The oral histories enabled Winslow and Clark (2005) to show that the hospice became a community in its own right, and many of those involved became part of ‘a family’ caring for the sick and poor (see chapter 5). They also demonstrated the role of communities in shaping the development of the hospice. Similarly, the oral history constructions utilized by Small (2000) gave a sense of the way protagonists on an individual level also shaped hospice development (see chapter 1). The work by Clark et al (2005) was identified as being important for three key reasons (in addition to those discussed in chapter 1). First, by advancing the development of end of life care as an

academic discipline it increased opportunities for scholarly research in this field. Second, it addressed some of the social and health inequalities because it challenged the rationality of exclusive care provision and advocated end of life care for all. Third, it also had an impact on the development of wider policy (Department of Health, 2008) (see chapter 1). Walmsley and Atkinson (2000) argue that when a collection of oral history stories are considered together they can be powerful, and have the potential to become a political document (see chapter 2). Walmsley and Atkinson (2000) recognized that there was a need to contextualize oral accounts in order to increase understandings. They could not make sense of the method until they knew more about events which were the backdrop to people's lives. Therefore, they also used documents to reconstruct local history because they helped to situate and contextualize the oral accounts.

Gallwey (2013) used archived oral history from the Millennium Memory Bank in her research, which was not about cancer care but it does show a different approach to the use of oral material to create history. Gallwey (2013) listened to recordings and derived a sense of continuity and change across the generations, which provided a broad historical picture of 'lived experiences' of single motherhood post dating 1945. Furthermore, it was also possible to link accounts with social mechanisms in the broader context to show how they impacted on daily life. For example, women explained how they managed to get administrators in the social and health departments to listen to them, by taking a copy of the Guardian newspaper to their meetings. This implied that if 'officials' thought the women were educated they perceived that they were also socially more influential than those who were not and were then prepared to listen to them.

There has been reluctance to conduct secondary analysis because it is assumed that users do not possess the same knowledge as the primary researcher about the context in which data was collected. Gallwey did not conduct the interviews she analysed unlike Thomas (2008) who re-analysed cancer narratives she collected earlier, so there was no opportunity to use interviewer/participant personalities to uncover stories or be part of the co-constructions. Yet secondary analysis should not be resisted because it might further our understandings about issues which we are fortunate enough to have archived. I would qualify this because a great deal of preparation/time goes into interviews and they can be exhausting, but the rewards may be great if previously untold stories are revealed. In re-analysis there is no opportunity to

unveil private experiences; instead the researcher generates a fresh reconstruction because they interpret accounts in the present which may reveal new understandings. In my study I used the oral history method to build on work by Clark et al (2005) and I will explain how this was achieved next.

3.2.3 Methods employed

Some of the participants I interviewed had provided oral histories for the Clark et al (2005) study, but rather than re-analysing accounts I interviewed individuals because I only had access to the earlier transcripts (not sound files). Besides, it was at least 10 years since the interviews were conducted and many interviewees had retired. I wanted to hear what participants had to say about the past in retirement because I thought they might have something different to say. In addition my work was focused on the 'local' rather than national or international developments. My method was driven by similar and different approaches to those taken in the oral history studies that I have discussed. I wanted to follow on the tradition of documenting life through the eyes of individuals who were breaking new ground and were on the margins of their professional community. Some had written short accounts about their work for a book published in autobiographical style by one of the retired local cancer support nurses - 'Dreams, Reflections, and Memories of CancerCare North Lancashire and South Lakeland' (Youren, 2007). I was able to uncover new narratives to those already given in this reflectively with time, to reveal how social and cultural issues impacted on each other to influence policy and practice (Gardini, 2012; Small, 2000) (see chapters 4-6). I formed a view that participants would probably feel on a fairly equal basis to me and should reveal interesting accounts because the cooperation afforded by this method is its main strength. Similarly the interviewer's intention guides but does not dictate the participant's accounts; therefore it leads to a co-construction of the past in the present (Thompson, 1988; Watson and Woods, 2005).

On a critical note there was a risk of monopolization (only obtaining a positive story if the sample consisted exclusively of supporters of the cancer and hospice services) because my study was about events occurring at a specific time, which related to a relatively small group of people in one community. The main challenge was that potentially it might have uncovered a 'collective story' or rather a 'single way' of developing services (Peniston-Bird, 2012).

Therefore it was essential to search for alternative explanations and paths (see chapter 2). Two key issues were identified as being significant in reducing the threat of monopolization. First, the risk was reduced by the collaborative and democratizing nature of oral history. Second, oral history revealed a network of contacts from a wider range than would have been the case if I had selected them, as I shall explain in detail shortly. Overall this approach provided a greater opportunity of discovering a complex and valuable form of history (Thompson, 1988; Thompson, 2000). I would qualify this though because there are limitations. For example, it can be difficult to reach ethnic minority voices because of the nature of the subject or perhaps since snowball sampling recruits from a connected network, and those on the margins might not be part of the group (Peniston-Bird, 2012). I will now report on the study site and how participants were recruited.

3.3 Site, participants and recruitment

The main purposes of this section are to describe the place where the research was conducted, illustrate that a broad range of participants were involved in the study and explain the recruitment process.

3.3.1 Venue

This study took place in the small North West city of Lancaster and surrounding district, the area stretched across a long thin strip of land to South Lakeland and across to Barrow-in-Furness on the North West Peninsula (Youren, 2007). Geographically, the area was quite varied. For example, urban Lancaster was the administrative centre, Barrow was more remote and South Lakeland was rural which attracted an affluent older person to retire into the region. At the relevant time in which this study was concerned the Lancaster District had a population around 220,000 (McIlmurray and Holdcroft, 1993).

Traditionally Lancaster had a mixed economy with a particular emphasis on the manufacture of linoleum and oilcloth and many service industries (Roberts, 2000). By 1981 however the area was suffering from an economic decline as a result of a nationwide recession, and many of these industries were under threat. It particularly hit the North of England because of a loss of manufacturing jobs, and there had also been general cuts in government spending

(Pettinger, 2012; Schifferes, 2009). The community included people from different social backgrounds. A local oral history study which focused on family and social life uncovered that it was customary for older people to be cared for by relatives/neighbours and die at home, younger people however tended to be admitted to the hospital as they neared the end of their lives¹. There were four main reasons detected as to why the City and the region underwent a change in the 1960s and 1970s. First, following the establishment of the University of Lancaster there was an influx of academics recruited to work at the University and some brought their families. Second, a large teacher training college was established and this also attracted new groups of people into the area. Third, there were a number of successful business ventures; a shopping centre was also built in the city centre which attracted retailers into the area. Fourth, there were expansions in manufacturing industries and a large extension built onto the nuclear power station at Heysham (four miles away from Lancaster). Consequently, there was relatively low socio-economic disadvantage in Lancaster.

Yet there were pockets of hardship and deprivation particularly in Morecambe Bay and Barrow. A number of significant issues were identified as being linked to these unequal social circumstances. First, there were high levels of unemployment due to the decline in popularity of Morecambe as a holiday resort; this had taken its toll on the area's historic fabric. Second, the West End Pier was washed away in a storm in 1977, the larger Central Pier was demolished due to structural unsoundness/neglect in 1992 and many properties were in a state of disrepair (Cherry, no date; English Heritage, 2007; National Piers Society, 2013). Third, Barrow had been a town of heavy industries including shipbuilding, engineering and the production of iron/steel but these had all declined (Roberts, 2000). Fourth, there was a considerable amount of asbestos related morbidity and mortality because of the shipbuilding; the area had the highest number of reported mesothelioma cases in the United Kingdom (Clayson, 2010).

3.3.2 Health care in the region

There were remnants of the large health institutions surviving into the 1980s '...such as The Royal Albert Hospital for long stay mentally-handicapped patients, the Moor Hospital – also long stay, Ridge Lea Psychiatric unit and the Royal Lancaster Infirmary...' (Youren, 2007, p.xi). There was also Beaumont Hospital in Lancaster, a hospital in Morecambe and one in

Kendal; all but the Lancaster Infirmary, Morecambe and Kendal hospitals were closed. By the early 1980s there was more of a tendency for people including elderly (if there was no family to care for them) to die in hospital, and attitudes amongst younger people changed as they became more questioning and wanted further information about illnesses².

In the early 1980s there were also Lancaster, District and Area Health Authorities the National Health Service had been separated in 1962 into hospitals, general practice and local health authorities. A key consequence of further restructuring in 1990 was that the National Health Service and Community Care Act (1990) introduced the internal market. Now health authorities managed budgets and bought in healthcare from hospitals/other organizations (National Health Service Choices, 2012) (see chapter 1). These changes were all taking place against a background of economic decline and political restructuring; the Conservative Government was elected in 1979 and remained in power until 1997 (British Broadcasting Corporation, 2014). In the next section I will reflect on my understanding of the developments and explain my choice of location.

3.3.3 Reflections on my understanding of the developments: choice of site

I will now provide some reflections of why I undertook this study in the way that I did. Having trained and worked as a cardio-thoracic intensive care and oncology nurse and graduated with a BSc (Hons) in Health Studies I received my postgraduate education at The University of Law (formerly The College Of Law), Guildford. During that period of training I studied *inter alia* medical law and undertook further solicitor's training. My nursing background, subsequent employment as a solicitor and the experience of personal loss of close family members all led to the development of my interest in cancer and palliative care services. These experiences highlighted three important issues. First, they raised my awareness of inequity in service provision. Second, they gave me more of an understanding of the importance of good care; people die once there is no second chance to 'get it right'. Third, sadly this is an eventuality that will happen to our family, friends and ourselves therefore we all have a vested interest in good services being available and accessible. Furthermore, when I studied for the Postgraduate Certificate in Health Research (End of Life Care) at Lancaster University I explored the history of hospices and palliative care at national and international levels. This made me think about the ways in which my oncology nursing years earlier bore

similarities to the approaches of those involved in hospices. For example, the focus was not just on physical illness as it had been conventionally, but also took emotional factors seriously (McIllmurray, Gorst, Holdcroft, 1986).

In addition, anecdotal evidence suggested that cancer and palliative care services in Lancaster were unusual because oncology, cancer support and palliative care developed alongside each other (Soothill and Thomas, 1988) (see chapter 1). Furthermore, in 1978 Malcolm McIllmurray a Consultant Physician with an interest in cancer was appointed, yet this was an uncommon position at district level because most appointments at that time were in teaching hospitals (see chapter 1). Prior to 1978 there was an outreach service consisting of a clinical oncologist from Manchester attending a clinic every two or three weeks (see chapter 4). Subsequently, in the early 1980s cancer support services emerged and evolved into the charity CancerCare. St John's Hospice, also a charity opened in 1985 and was originally managed by nuns and nurses with input from a general practitioner and Malcolm McIllmurray (see chapter 4). Whilst undertaking the further study at Lancaster University I formed the view that research exploring how cancer *and* palliative care services developed at the local level would make a very interesting analysis for my PhD thesis, and researchers had not previously done this. In addition, the place was also convenient because it is where I live.

During a period of instruction as a doctoral research student of Professor David Clark and Professor Nick Watson I developed my research interest further using oral history. In addition I explored ways in which accounts could be better understood by applying elements of social constructionism from work by Pinch and Bijker (1984) (see chapter 2). My training and experience have led me to concentrate my research efforts on the oral history of the development of cancer and palliative care services in one place.

3.3.4 Participants

I wanted to capture multi dimensional accounts from participants because these had the propensity to challenge rationality, reduce the risk of a linear (similar) story and search out different experiences about how services developed (Nicolson and McLaughlin, 1987; Pinch and Bijker, 1984). Therefore I decided to include a wide range of individuals from hospice and cancer support staff - managers, drivers, trustees, administrators, volunteers, hypnotherapist,

physiotherapist, counsellor, retired general practitioners/consultants and former nurses. Participants will be introduced when they are referred to in the thesis for the first time, I did not know at the outset how many would be identified, how many would accept my invitation or whether there would even be a sufficient number.

3.3.5 Recruitment

In order to recruit participants I obtained research ethics approval from the Faculty of Law, Business and Social Sciences (now The College of Social Sciences) at the University of Glasgow. Ethical considerations involved balancing advantages against potential disadvantages and producing good quality research; the overarching factor was to protect participants' dignity, rights, safety and well-being (Booth, Colomb, Williams, 1995; Department of Health, 2005). The lack of scholarship on how local services develop *ipso facto* demonstrated the study was needed, and it was also ethical because there was a gap in our knowledge (Royal College of Nursing, 2009). Before embarking on this research I considered including those in the National Health Service, but after discussion with my supervisors decided against this because it was clear that there would be enough data from those involved in the cancer support and hospice services. There were three key reasons for focusing on the period 1976-2000. First, this captured accounts of what it was like to care for people with cancer and palliative care needs before there were any specialist facilities. Second, it also covered the era when those at the grass roots were setting up services. Third, it ends when there was overarching policy (Department of Health, 2000). Although patients' experiences have not been directly sought many of the participants used these when talking about their own involvement, so they are acknowledged through the narratives.

3.3.6 Snowball sample

I used 'snowball' sampling to recruit participants because I wanted a sample that would lead to the generation of theory and facilitate a wider appreciation of the social processes that took place, as cancer and palliative care services developed (Arber, 1993). It was not a situation that called for any inferences to be made about the general population (Ozanne et al., 2009). In contrast, oral history enabled me to choose precisely whom to interview in a similar way to that described by Thompson (1988). This was because of the networks that existed between

individuals sharing certain characteristics. However, with the exception of the first person I interviewed I did not actually choose the participants. In fact, the participants identified all those who took part; I believed this would reduce claims of researcher recruitment selection bias and help to make the study credible. Problems have been shown to arise if participants with the 'same' characteristics are recruited because accounts can be similar making it difficult to critique the phenomena under study. It was one of the challenges initially experienced by Dore (2012) in work that collaborated with researchers who recruited via 'official' channels. Dore (2012) challenged the rational official story by asking diverse acquaintances to recommend interviewees, and they in turn suggested others so that there was a broad range of actors. In relation to my study I knew one of the oldest retired doctors in the area - Roger Lomax, who I hoped would describe what it was like to care for people before any cancer/palliative care services existed.

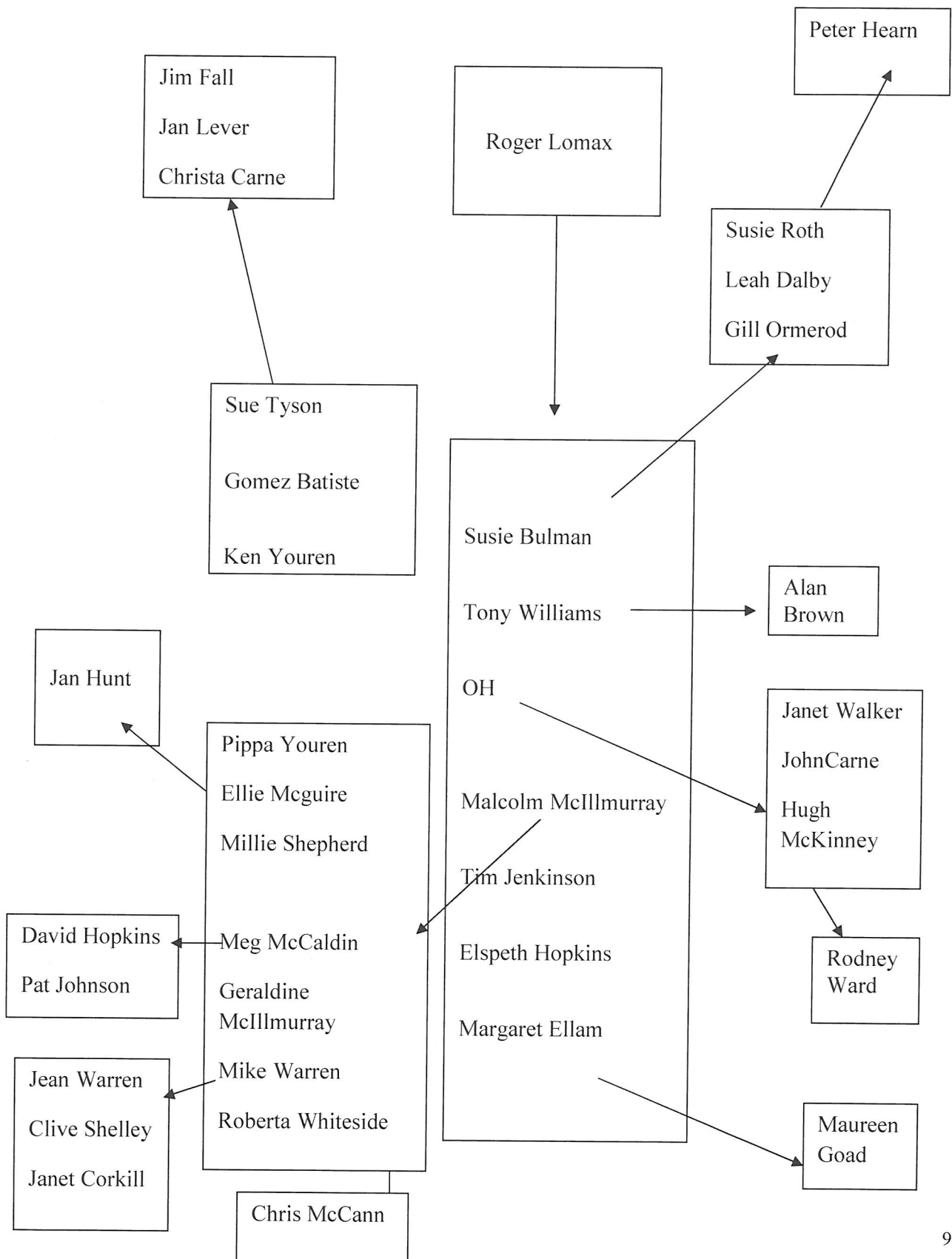
Whilst I wanted to reach a wide group I also needed one that was firmly grounded on the central issue - those who played key roles in developing services and effecting change. Therefore I invited Roger Lomax to take part by sending him a letter explaining the study (Letter at Appendix 1, p.236. Information Sheet at Appendix 2, p.237 and Consent and Clearance form at Appendix 3, p.240). During the interview he suggested other potentially suitable individuals, and I found that identification and recruitment literally 'snowballed' from that first encounter. Arber (1993) argues that this is one of the key strengths of the method because it reveals a network and allows triangulation. The participants shared characteristics such as experience of caring/supporting people with cancer and those nearing the end of life in the area between 1976 and 2000. I carried out searches to find people who had been suggested as participants but had relocated because to ignore migration would have excluded them and reduced the possibility of capturing different perspectives. Once a potential source was suggested I sent a letter explaining the study and inviting them to take part, I provided my telephone number so they could make contact if they wished.

I informed potential participants which person had made the nomination because I anticipated it would reassure people to know that someone they knew had already taken part and put me in touch. Individuals reacted positively and this was reflected in the overwhelming majority agreeing to participate. Some told me that they had spoken to potential sources about my study before suggesting I contact them. I considered the ethical implications and took the view that it

was unlikely people would feel coerced, they were not vulnerable like some patients, they were competent adults and many were strong charismatic characters. On the contrary, I thought it more likely that people would only get in touch if they wanted to become involved. Having individuals discuss the study with prospective participants was a positive and unavoidable feature of the sampling method. After all I was recruiting from a connected network, located in a small geographical community; many people knew each other so it was not surprising they talked amongst themselves. Each time I interviewed someone I asked whether they knew anyone with the required characteristics, in a similar way to Riley and Fenton (2007). On a critical point that study explored carers' views and the group were brought together because of family illnesses. Those involved in cancer/palliative care in my study were more likely to have come together out of choice or interests because of shared values about care. I continued interviewing until there was nothing new being gained, and I had reached saturation (Glaser and Strauss, 1967).

One way of reducing potential bias in a snowball sample might have been to place an advertisement in the local newspaper inviting people to participate. However, once interviews were underway I believe participants would have made recommendations about prospective sources anyway. I kept a record of who recommended whom each time a participant nominated a person not previously mentioned (figure 1). I also recorded every name suggested by each participant regardless of whether another participant had nominated the same person (Figure 2 at Appendix 4, p.242). This demonstrated that multifarious accounts were gathered from different sources and indicated the importance participants placed on individuals whose names came up time and time again.

Figure 1: Snowball Sample



3.4 Interviews

In this section I describe the interview process and the dynamic questions/topics formulated. When prospective participants made contact I asked whether they had any documents relating to the services or their experiences of starting them. The response was positive and meetings were set up at mutually convenient times. I personally carried out all the face to face interviews between March and December 2010. I have many years experience of interviewing seriously ill patients as a nurse and solicitor in order to ascertain how illness impacts on daily life. I have also interviewed health professionals in order to reconstruct events which have arisen in practice. In addition I undertook training on interview techniques as part of the Postgraduate Certificate in Health Research (End of Life) at Lancaster University. I also attended 'Oral History Training' with the Oral History Society at the British Library, which involved practical role-play interview techniques. I joined The Oral History Society in order to gain access to other research and researchers using this method.

I anticipated the interview experience would be an act of reciprocity because of the co-operative nature of oral history (Brannen, 2005; Clark, 1997). Participants were aware from the Information Sheet that the purpose of the research was to increase understandings on how local services developed during the relevant period; in return for taking part they were encouraged to tell their story in the context of their life. All except two interviews took place at participant's homes because that was where I thought they would be most at ease and able to provide detailed testimony (Winslow, 2009). Two were conducted at my home because it was more convenient for participants.

At the start of the meeting I reiterated the details on the Information Sheet, explained that participants would be credited for their contribution in the recording/transcript in accordance with the Oral History Society (2009) guidelines. Therefore they would be identifiable unless they wanted to be anonymous. All except one participant were happy to be named. I described the purpose of the consent and clearance form. Furthermore, I assessed mental capacity by talking, listening and forming a view as to whether people could understand, retain and weigh up information in order to make a decision about participating; this ensured informed consent was obtained (Bulmer 2008; Medical Defence Union, 2011; Mental Capacity Act, 2005). These essential requirements are based on the principles of autonomy, beneficence, non-

maleficence and justice and ensure risk is in proportion to benefit (Barrett and Coleman, 2005; Department of Health, 2005; Gillon, 1992; Oral History Society, 2009). Risk relates to potential physical, psychological, social harm, privacy and personal values (Medical Research Council, 2009; Royal College of Nursing, 2009). After the interviews all participants were happy to assign copyright to the Custodians of the Library at the University of Glasgow. The interviews were digitally recorded using Olympus VN-5500PC and have been preserved as a permanent reference source. The recordings will be archived at the University of Glasgow library so they can be used in future studies, and this may also promote collaboration between researchers (Perks, 2001). Thirty five people were interviewed (Table at Appendix 5, p.243), 14 were male, 21 female. Of these eight covered the period before specialist services began, 16 were involved in 'breaking new ground' and 11 talked about the years after services were established.

Table 3.4 (a) Anonymous table by gender

ROLE	FEMALE	MALE
Doctor	1	9
Nurse	10	0
Therapist	4	1
Volunteer/trustee	2	2
Administrator/secretary	3	0
General Manager/CEO	0	3

Most interviews lasted about 1 hour:

Table 3.4 (b) Quantum of recordings and transcripts generated by interviews

	QUANTUM OF INTERVIEWS
Number of participants	35
Number of recording hours	43 hours 40 minutes
Shortest interview time	28 minutes
Longest interview time	2 hours 15 minutes
Average	1 hour 15 minutes (28 pages) (10,455 words)
Total number of pages of transcripts	1075
Shortest transcript	14 pages (5372 words)
Longest transcript	71 pages (21,362 words)

I also consulted transcripts from the Hospice History Project (1995) of interviews with people involved in cancer and palliative care in the district (Table at Appendix 6, p.248).

3.5 Formulation of flexible questions/topics

Initial questions (List at Appendix 7, p.249) were created following my literature review of the modern hospice movement and development of cancer and palliative care services. Some topics arose inductively from interviews. For example, I soon formed a view that participants perceived they had been part of something special, and I formulated questions about how it felt to be involved for subsequent interviews. Questions were flexible depending on what had been said in previous interviews and were created to suit participants' particular backgrounds. I hoped participants would raise these topics without being prompted because it would then be easier to probe for more information about issues that seemed important (extracts of transcript marked up for process issues as well as for analysis issues at Appendix 8, p.251).

I found that repeating a word introduced by a participant was often a good way of probing for more information about something that appeared significant because of what was uttered or how it was said. Some individuals talked about topics without any prompting, I asked questions about issues raised and invited them to say a little bit more or explain what they meant by what they had said. However, for those who did not raise topics relating to the core questions I used the prepared list purposively to ensure that similar themes were covered in many of the interviews.

3.5.1 Examples of core questions

The questions were not necessarily discussed in the order in which they feature on the list and depended on what participants told me. Whilst I have separated the questions out they were not always mutually exclusive, some responses unravelled in an overlapping manner:

a) Place of birth, religion and family life

I took the view that participants would be more relaxed if I started with something that could be answered without much thought. I hoped they would then be able to provide more detailed information than they would if they were anxious. I wanted to know about the role of religion as it featured in readings on the hospice movement often drawing people to this area. I asked participants to say a little bit about their family, which increased understanding of participants' experiences in the context of life.

b) When did individuals choose their occupation and why?

I was curious to know what triggered the idea of becoming a nurse, doctor, physiotherapist, complementary therapist or volunteer and when this was. I wanted to know whether decisions were linked to past experiences.

c) What brought individuals to Lancaster and when?

I wanted to capture stories about what attracted people to the location to see whether there were any commonalities/variations. I was interested in whether individuals originated from the area or had moved in from another region. The date of arrival was important as I needed to know what the scene was like before services existed, what it was like when organizations began and how they changed in the course of time.

d) How did individuals come to be involved in cancer and palliative care?

I was intrigued to ascertain whether past experiences led participants into this work because my readings indicated that previous encounters were the catalyst for the modern hospice movement (Saunders, 1965; Saunders, 1974; Saunders, 2000; Saunders, 2001a; Saunders, 2003). I wanted to increase understanding about what drew people to this work (overlaps with (b)).

e) What was the philosophy of care?

I was curious to find out about the philosophy and whether it was linked to past experiences. I wanted to capture stories about the ideology underpinning training, particularly in relation to caring for people with cancer and those who were dying. I wondered how people felt about this aspect of training and whether specific incidents guided them into cancer/palliative care later on. I wanted to know more about philosophy to see whether there were any themes, commonalities and differences. I asked participants to say a little bit about their philosophy by explaining how they provided care and support. I was interested in ascertaining where people were cared for, by whom and what they were told about their illnesses. Many participants raised the concept of holistic care before being specifically asked and reflected on mechanical and holistic practices they had encountered in the course of time. I was intrigued about the purpose of care because I wanted to know whether curative or palliative goals were embedded in the thinking. I wanted to know about the way people worked and whether participants saw those with cancer who were relatively well, in addition to those who were reaching the end of their life. I asked participants to tell me about experiences of working in a multidisciplinary team, their perspectives on the new services and how others received them.

f) Did they feel part of something unique and special?

I asked how it felt to be part of the organizations because I wanted to know whether participants perceived they were part of a special group. I mentioned earlier that this question arose inductively out of the interviews.

g) How was pain managed?

I invited participants to talk about management in the course of time (overlaps with (e)). I wanted to capture accounts about drugs used and other methods such as spiritual care and complementary therapies.

h) What links and bonds were forged between/across organizations?

I was interested in the bonds between cancer support services and the hospice and how these changed. I asked about links and probed for more information about things that seemed important (overlaps with (e)).

i) Paths not taken

I wanted to know why the cancer support service and hospice did not merge and this question arose inductively from the interviews. For example, Meg McCaldin had many roles at CancerCare (volunteer, relaxation therapist, Manager and hypnotherapist). She formed a view that CancerCare needed to remain independent in order to safeguard its philosophy (McCaldin, 2010)³ (see chapters 5-6).

j) Charismatic leaders

I decided not to ask direct questions about leaders because to do so could have been intrusive, acted as a barrier to rapport and ultimately produced less rich accounts. Instead participants were asked how they came to be involved, how they worked and were treated by the multi-disciplinary team. I enquired how they generated support for their projects. If participants indicated there was friction/hostility, I asked them to say more about what they meant and how they dealt with matters. I have explained that my study involved a wide group and I wanted to capture accounts about the importance participants placed on the pioneers. Again I asked them to talk about their experiences of cancer/palliative care rather than raising direct questions about charisma *per se*.

k) Routinization and bureaucracy

These topics overlapped with philosophy and how people worked before the introduction of cancer/palliative care services. I wanted to discover whether 'small was beautiful', a perspective shared by some (see chapter 5). I was intrigued to know if routinization and bureaucracy were inevitable consequences of growth. I waited for nuances to arise whilst discussing other topics before probing for deeper information. For example, if a participant

made a passing comment related to bureaucracy such as an organization changing to become more 'business like', I asked what they meant. I did not raise questions on this topic directly as I did not want to discourage openness or give the impression I was being critical of change.

l) Research and education

Participants were asked whether they had taken part in any research in the relevant period and about any training. I was concerned to learn about an evidence base for practice and what education existed.

m) Changes and challenges

Towards the end of the interviews I asked what participants considered were the greatest changes and challenges to the way they worked and why. This was successful in generating accounts of some of the most difficult experiences and explanations as to why (see chapter 6).

n) Anything else

I provided an opportunity for participants to raise any other issue they considered important. Generally, participants confirmed they had discussed everything they wanted to cover. Overall, the interviews provided an opportunity to discover experiences, sense emotions, explore important issues and direct questions to uncover accounts through co-construction (Lars-Christer, 1997; Winslow, 2009).

3.6 Documentary sources

A number of documentary sources were used in this study and the tables at Appendices 9 and 10 indicate the quantity of documents that were generated by the cancer support service and St John's Hospice (see pages 257 and 262).

3.6.1 Introduction to documents

Although the primary focus of this study was on oral history, I tried where possible to support those data with documentary sources. I wanted to find official documents that portrayed local developments and also informal projects and papers which recorded experiences. I envisaged from the outset that there would be documents, but I did not know how many. The participants provided documents in the form of articles, books, projects and papers about the services. Similarly, St John's Hospice and CancerCare kindly provided a large number of papers. These included Minutes of Meetings, journal articles, correspondence, newsletters, a documentary film (see chapter 5), plans, policies, reports, information leaflets, documents relating to conferences and Declaration of Trust Deeds.

Sometimes I found documents first then during interviews I asked participants to say more about the text and was able to tap into information at a deeper level. In addition, I also found documents that corroborated oral accounts. Therefore my study generated different forms of documentary evidence (Tables at Appendix 9, p.257 and Appendix 10, p.262).

There were four key reasons identified as to why the documentary sources were particularly useful. First, I found minutes of meetings helpful in piecing together when events had occurred in the course of time. Second, there were also important articles about art/craft projects, which indicated there was a desire to try and understand what it was like to have cancer or face the last stage of life. Third, local magazines published stories from individuals about their experiences before any specialist services existed and then later as facilities were created and developed. I was able to consider these in the light of the accounts to show that they corroborated stories about the importance of emotional problems, and the requirement for supportive/palliative care services to help meet needs. Fourth, some of the documents provided background context which enabled connections to be made with wider social, economic and political mechanisms. For example, they uncovered information about fund raising which linked developments to major donations from donors such as the Multiple Sclerosis Society (see chapter 4). The next section looks at the approach taken to analysing data.

3.7 Approach to analysis

Oral history can be presented in a number of ways. For example, Studs Terkel simply took what had been said at ‘face value’, and presented the narratives for the reader to form a conclusion rather than the researcher performing deconstructive analysis (Davies, 2010). It could be a powerful way of giving a voice to the storyteller. Yet quotations rarely speak for themselves, they need to be unpacked because interpretation makes connections and findings that the reader or participant might not appreciate (Booth, Colomb, Williams, 1995). I knew from the outset that I would need to analyse data because I wanted to obtain fruits not previously harvested about how local services developed. Thompson (1988) argues ‘...the voice of the past matters to the present’ (Thompson, 1988, p.viii) and I hoped that focusing on accounts would increase understandings of the history of developments, and the mechanisms that shaped them in the relevant period. Ultimately this would address my research aims (see Introduction). It is generally considered that there are three ways to present oral history in written summary (Clark et al., 2005; Thompson, 1988):

‘First, one tells the story of an individual’s life. Second...select and group material from different individuals that engages with the same theme; when grouped together...see how experiences were similar and...highlight contrasting stories. Third...oral history is used to shape and illustrate a particular historical interpretation...’ (Clark et al., 2005, p.8).

I chose the second approach and used thematic analysis because I hoped this would identify longitudinal and cross-sectional themes pervading transcripts and documents (Bailey et al., 2002). Furthermore, Overcash (2003) found that analysing and interpreting accounts provided valuable insight into decisions about health practices that could guide service development. However on a critical note, during the process steps must be taken to ensure phenomena are not taken out of context as I shall explain in the analysis section.

Some participants were the inspiration behind services and had worked in the ‘same’ places in similar periods so were able to reflect on related events, and I wanted to compare accounts to see whether there were similarities/disparities in changing patterns. Others were involved in caring for people in the area but had not worked in the cancer support services or the hospice,

and I wanted to compare experiences with those that had been involved in the specialist organizations to see whether they shared or had different understandings about care.

I envisaged that I would code the oral history by listening to recordings and reading transcripts iteratively in my search for emerging themes (Skilbeck et al., 2005). One critical issue was how to ensure the process was credible; I decided to use researcher triangulation with my supervisor acting as a checker because there is no 'right' way to do coding (Cohen Fineberg, 2010). My justification being that if we came to the same conclusions about the meaning of the data it would improve consistency, make the research rigorous, trustworthy and credible (Chappel, Ziebland and McPherson, 2006; Fielding and Fielding, 1986 cited by Fielding and Schreier, 2001; Mallinson, 2009; Payne, 2007; Spencer et al., 2003). I drew on material from an extensive group with a variety of perspectives so this also increased credibility because interpretation '...becomes credible when the pattern of evidence is consistent, and is drawn from more than one viewpoint' (Thompson, 1988, p.248) (see next section).

3.7.1 Analysis

Preliminary analysis started at an early stage during the interviews when participants' recollections led me to formulate further questions for future interviews (see 3.5.1). One analytical observation I made was that key players applied their philosophy (to provide accurate information and holistic cancer and palliative care) across different settings (hospice, CancerCare and oncology). This created a thread for collaboration, continuity of care and comprehensive services. It indicates how early in the research process less formal means of analysis started to take place because at the same time as collecting evidence, I became creatively '...involved in assessing it' (Thompson, 1988, p.167).

Once the transcripts were typed I began a more in depth process using thematic analysis coupled with constant comparison (a process in which themes emerging from the transcripts are compared with themes arising in other transcripts in order to code the data) (Glaser and Strauss, 1967). There were three important reasons which provide a defence for using this technique. First, it can lead to richer findings than content analysis (Donovan and Sanders, 2005; Pope, Ziebland and Mays, 2000). Second, it has been used successfully in research relating to perspectives on end of life care (Bowman and Singer, 2001), patients' experiences

of palliative care (Seymour et al., 2003), place of death (Thomas, 2005), preparing and planning for the end of life (Davidson and Simpson, 2006; Seymour et al., 2004; Steinhäuser et al., 2001), the specialist palliative care nurse (Chapple, Ziebland and McPherson, 2006) and hospice patients' views on research (Terry et al., 2006). Third, the method has also been used in a number of studies involving health research in other fields (Appleton, 1995; Reid et al., 2009).

I scrutinized research papers emanating from these studies to see how the researchers had used constant comparison to analyse data, which proved a very useful exercise and I was able to adapt the processes in my study. I analysed data by carefully reading a number of transcripts, I concentrated very hard and focused on every word as advocated by Mallinson (2009). I did not annotate the transcripts at this stage because I wanted to see whether intuitively similar themes were emerging. Part of me felt a little apprehensive and also excited as I began sifting through the data that had been enthusiastically gathered and generously given in the course of 2010. My initial reaction was one of feeling rather overwhelmed by the voluminous transcripts and daunting task that lay ahead in order to make sense of them. I wondered how to deal with them, how to root out topics and codes, how to draw together themes running across the transcripts and how to determine whether there was an overarching theme to each interview. I decided that in order to conquer the analysis a practical approach was needed. Four key steps were necessary in this process. First, there was a need to take one step at a time and carry out the 'same' procedure on each transcript. Second, I needed to give a clear step-by-step account of the analysis process because it has been found that the methods used impact on the objects of enquiry (Mays and Pope, 1995; Mays and Pope, 2000; Pope, Ziebland and Mays, 2000). Third, I also read the reflective notes I made after each interview and fourth, I listened to the recording of the transcript I was reading. The approach enabled me to focus on accounts, sense what was important and start to form a picture about the meaning individuals attached to certain experiences.

I re-read and scrutinized transcripts and compared text across transcripts to see whether similar, new or different themes emerged. Then I started annotating transcripts in pencil at first with themes and words that emerged from the page, using the individual's vocabulary where possible to reduce possible misinterpretation (Clayton et al., 2005). When I identified a word or sentence which related to a particular theme, I also started to note the words by hand

initially on a separate sheet of paper. When I identified a different word to the one singled out earlier but which related to the same theme as the previous one, I also entered this word onto the sheet. This process of producing descriptions of data and identifying codes in order to begin the categorization of data is content (descriptive) analysis, and it is the first stage in thematic analysis (Donovan and Sanders, 2005). The system enabled me to build five lists of recurring themes; I created headings for each list together with colour codes:

Table 3.7.1 (a) Themes and colour codes

THEME	COLOUR
Charisma	Pink
From Scratch to Routine	Yellow
Across Organisations	Orange
Power Struggles	Blue
Philosophy	Green

I continued applying themes that emerged from transcripts I had read to data in other transcripts. Coloured pens were used to highlight individual words or sentences in the transcripts that related to themes. This was time consuming as it required total immersion whilst I read iteratively, comparing text in a process of ‘...constant comparison...’ (Donovan and Sanders, 2005, p.520). Themes were derived inductively from the transcripts that I had read, and then they were applied to data in other transcripts as I read them. It was an overlapping process as new or recurring themes emerged; it enabled descriptive accounts to be produced using the themes as a framework as well as the themes emerging from the transcripts in the first instance. The theme ‘Philosophy’ contained the most information therefore I divided it into ‘Philosophy of Care’ and ‘Philosophy of Practice’ so it was manageable. I transferred the hand written words (I had selected from transcripts because they related to themes) that I had entered onto the A4 sheets into a table (Table of extracts at Appendix 11,

p.264) and prepared another table for the coding of transcripts relating to philosophy of care and practice (Table of extracts at Appendix 12, p.266). When I reached this stage instead of simply continuing to add a word to the thematic lists (that is - Appendices 11 and 12), I was able to describe the section of text that related to a particular theme and my interpretation of it, so more detailed tables were needed to demonstrate the procedure. I set up six tables, one for each theme and began cutting and pasting sections of text that related to each theme into appropriate tables. I started with the theme 'charisma' and entered sections of text relating to charisma from across the transcripts. I highlighted the words within the text that were linked to 'charisma' or whatever the theme was. I noted the initials of the individual and the page number where the text could be located in the transcript so that it could be checked for more detail at a later stage. I then described the text by reading it and I continued to ask myself 'what was going on here?'

I wanted to know what similarities and differences there were in the themes in each transcript and across all the transcripts. I recorded my interpretation of the text in a separate column on the table. In another row I noted some reflexive diary comments about what it was in my background and research interests that I considered had led me to interpret the text in a particular way. Finally, in another column I listed related documentary sources so these could be pored over later. Extracts from the table showing how constant comparison was used to interpret and theorize 'charisma' are below:

Table 3.7.1 (b) Charisma

NAME	THEME Charisma (To allow content analysis/descriptive data analysis)	SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES (Descriptive accounts of themes – what is going on here? Explanations for the data (theory))	REFLEXIVITY (What is it in my background and research interests that affect what I see and how I code this text?)	DOCUMENTS
Rodney p.23	...let's face it. In the 1985 to '90 period...you became a trustee because somebody knew you.	Connected network Became trustee because somebody knew you (invited you)	I am aware from my earlier readings that many of the pioneers of the Modern Hospice Movement were well connected in their communities. Connected networks are a common feature of charismatic characters.	Minutes of Meetings of Trustees
PH p.2	...it would have been a Meg McCaldin link...we	Connected network. There were earlier links with NCT.	I am aware from interviews that Meg then set up	Book – Dreams Reflections Memories

	knew Meg from...National Childbirth Trust...	Later but still in the early days of CancerCare/hospice PH's wife had cancer and used services (was also a hospice volunteer)	relaxation therapy at CC. Later PH became general manager so many connections developed	
PJ p.3	...it was really a lot of word of mouth, the fact that Meg McCaldin knew quite a lot of people who had contacts, Pippa did and people were recommended	Connected network Word of mouth – brought people in to provide supportive services	I am aware from other interviews that there were connections and from my experience charismatic leaders are very good at networking in order to generate support	CancerCare Minutes. Book – Dreams, Reflections, Memories
Rodney p.4	...driven by the dreams of Aine...dreams of Malcolm McIlmurray...were in many ways the driving force...Aine was remarkable	Charisma, Dreams, Driven, Remarkable These are all characteristics of charismatic individuals. Having a dream and desire to 'do things better' - a common feature	I am interpreting in this way because of readings on the Hospice Movement and charisma.	Minutes of Meetings of Trustees

(Extracts from Tables showing how constant comparison was used to interpret and theorize themes ‘Scratch to Routine’, ‘Across Organisations’, ‘Philosophy of Care’, ‘Philosophy of Practice’ and ‘Struggles’ at Appendices 13, p.268, 14, p.270, 15, p.272, 16, p.274 and 17, p.276 respectively). In addition to the cross sectional analysis I also formed an impression of each interview as a whole by capturing the overall shape of the narrative, to determine whether there was a dominant story line. When I had read through a transcript I asked myself ‘what was the golden thread running through the interview?’ ‘Was there a recurring story?’ I made a handwritten note on the front of the transcript to indicate any overarching theme.

I have explained how the researcher takes on an interpretive role when collecting and analysing data, and therefore the impact of these processes on knowledge generated is made clear through reflexivity (Clark, 1997; Malterud, 2002). In my study the evolution of thoughts, beliefs, decisions and processes demonstrating how the research was carried out were illustrated in a research diary (consisting of a scoping document, handmade notes, reflections following interviews and notes made in the data analysis thematic tables). I have demonstrated that during the analysis I kept asking myself what it was in my own background that was making me interpret data in a particular way. The scoping document and thematic tables were discussed during supervisory sessions and at meetings throughout the study and are available for scrutiny, which also increases transparency and trustworthiness (Mallinson, 2009). Lincoln and Guba (1985) (cited by Emden and Sandelowski, 1998) advocate reflexivity as an alternative conception of reliability. There is no assumption that another researcher could apply concepts in the ‘same’ way, or generate an identical interpretation because the social world is in a perpetual flux of construction (Weber, 1925 cited by Camic, Gordski, Trubek, 2005). There is a range of subjective perspectives to capture in creative motion like the babbling river described by Thomas et al (2009) rather than a single truth (see chapter 2) (Bailey et al., 2002; Watson et al., 1999). By way of illustration, as I analysed my data I looked out of my window in Lancaster, various phenomena were identified as illustrating a perpetually changing world. Nature was hibernating in all its glorious winter form; deciduous trees were bare, like black ebony, the ground was white with snow that changed to gold and peach by the rays of the vibrant climbing sunshine. Robins, blackbirds and magpies gathered titbits. These were tangible but they were not static, fixed in time objects because they were in a constant flux and existed in a shifting landscape. The point of this being that the scene was not the ‘same’, it changed and was open to interpretation at different stages. Similarly oral

history accounts also revealed a dynamic cancer and palliative care landscape which changed in the course of time (Craggs and King, 2013). Overall, the data was presented thematically in order to get a sense of the richness of experiences and increase understandings of factors that shaped cancer and palliative care services. It was useful to be able to quantify certain elements so there are tables indicating the number and length of interviews, transcript pages and words generated by those interviews. There are also tables indicating the quantum of documents because this also demonstrates the scale of work involved in the study. The next section provides more details of my impressions of the interview experience.

3.8 Reflections: the interview experience

Interviews provided an opportunity to ask questions about how participants felt about topics and the meaning of things of importance. Throughout data generation I followed Thompson's advice and asked myself on whose authority was my reconstruction based? In other words '...whose is the voice of the past?' (Thompson, 1988, p.viii). I explained earlier that interviews generated co-constructed accounts, determined by participants and what they wanted to say and also by my presence and questions. The more interviews I conducted the better I was at detecting nuances so that if something was said that seemed significant, participants were asked to say more about what they meant or how they felt. This increased my understanding of meaning behind experiences. I learned how to listen and I tried not to show any shock or surprise, whilst at the same time I conveyed continued interest in what was said. I am of the view that this encouraged people to say more about a topic than they might otherwise have done, if I had given the impression I was being judgmental. Besides, it was important to provide a balanced reconstruction using the differing accounts (Pinch and Bijker, 1984; Thompson, 1988). I tried to find evidence of individual perspectives rather than looking for true or false accounts (Fingerroos and Haanpaa, 2012). After all this was an oral history constructed by those involved at a particular time and uncovered individual perceptions of reality (Peniston-Bird, 2012; Winslow, 2009) (see chapters 4-6).

Some participants talked about very personal stories that related to caring for a particular person as they neared the end of life. One impression I formed was that if direct questions were asked they would be less likely to produce the kind of detailed stories that eventually unraveled. Talking in a broad fashion about care at the hospice/CancerCare and how people

were treated as they became closer to the end of life, focused the co-constructions until they centered on experiences of specific individuals/situations. It was then possible to tease out the philosophy of care and reveal the meaning of compassion, and how compassionate care was provided at the end of life. It was an emotional process for both actors as the stage was set and the scene unfolded. I shed some tears along with participants as a result of my interpretation of what I was told. I see this as a reflection of being human and expressing feelings; I think it helped people to say more when they realized I was sensitive to what they were saying.

During the interviews I kept asking myself ‘what was going on here in Lancaster?’ I looked to see whether there were any patterns emerging of which participants were unaware. Some told me about situations they did not want to be on tape and it was important to keep them confidential. Yet I felt they might be important for my understanding later when analysing data. Therefore, I made reflective field notes as soon as possible after each interview, usually in my car immediately on leaving a participant’s home. Sometimes interviews were interrupted with visitors but as a guest one cannot readily control the environment. One quality of being a successful researcher and getting the most out of a situation is learning to operate within the constraints. This was important as participants were probably more relaxed when surrounded by familiarity (Davis, 2010). Whilst I captured a few noises on some recordings this was an acceptable trade off for the rich accounts that might not have unfolded in more sanitized settings.

I also found the documents provided background to the services and ultimately helped connections to be made with social, individual, historical, economic and political mechanisms (see chapters 4-7). In addition I used oral history to check my interpretation of documents. For example, before interviewing Pippa Youren I read her book about cancer care work, during the interview I sought clarification of my understanding and probed for explanations. It was particularly useful in illuminating personal experiences - Pippa wrote ‘...it is an advantage if the healer has personal experience of grief...and has resolved issues thrown up by the experience of loss’ (Youren, 2007, p.54). I asked Pippa to say a little more about what she meant, she reflected on the loss of her child which she believed was important in her work because it made her realize there was little point in treating the patient alone, family support was so important. This increased my understanding of Pippa and her work in the context of her life (see chapter 5).

I did not intentionally exclude anyone from the interviews; however, some were too ill to take part, some had died or could not be traced and were unavoidably absent. The Nuns had retired to Northern Ireland and did not wish to take part; the reason given was that they did not want to get involved in research. Payne argues that ‘we need to be doing research with people who say: ‘Thanks but no thanks...’ (Jackson, 2013, no page) because if they are excluded their voices will not be heard. Perhaps there is another story to tell. There were others I could have interviewed but after 35 I reached saturation because I was not gathering any new information (Bowman and Singer, 2001; Curtis et al., 2002; Glaser and Strauss, 1967). This was a significant but manageable quantity given the time limits/resources, and it would have been unethical to gather data if nothing new was being learned (Clark, 1997).

Interviews were transcribed verbatim and included laughter, crying and long pauses. The repetitive errs and ahs were left out because transcribing was very time consuming and would have been more protracted had they been included. Furthermore they could not be usefully analysed, after seeking the opinion of my supervisors I decided to leave them out. In this section I have provided a detailed step-by-step account of the approach to data analysis and interpretation. The material used was stored securely, computers were password protected, personal information was kept confidential and accessed only by my supervisors and me in compliance with the Data Protection Act (1998).

3.9 Summary

This chapter has dealt with the oral history method in detail, it explained how I approached it and directed the material so that oral history and documentary sources created the constructions which I was able to analyse, interpret and make sense of. Chapter 2 explored some of the historical methodological challenges in health research. It examined how social constructionism could increase understandings of accounts because oral history epistemology resonates with some theoretical constructs embedded in social constructionism. I defend the design as being the most appropriate because by focusing on oral history it was possible to apply some elements of social constructionism to understand more about the accounts. Chapter 2 explained that this was because oral history and social constructionism challenge rationality (for example, a physical focus) and seek out differing views, ways and explanations. They empathize with relativism, different experiences are not judged to be better

or worse than others because the methodology is democratizing (Pinch and Bijker, 1984). Moreover, in chapters 4-6 I will show how I fused both ‘...facts and interpretation...’ (Thompson, 1988, p.255) into new theory, or ‘...thick description...’ (Thompson, 1988, p.255) using this design by linking experiences to wider contextual factors.

The method coupled with its underpinning methodology enabled me to reveal developments at the macro level and show how these changed in the course of time. It also enabled me to address aim 1 – ‘to ascertain how individuals developed cancer and palliative care services in one community’, aim 3 – ‘to place the research findings about service development in the wider context of cancer and palliative care issues’ and aim 4 – ‘to increase understandings about the development of cancer and end of life care provision over time’ (see Introduction and chapters 4 - 7). At the micro level of local developments I formed an impression that the method and methodology were particularly suited to addressing aim 2 – ‘to capture experiences of how care was provided at the end of life’ (see Introduction and chapter 5). Moreover, I was able ultimately to answer the overarching research question - ‘How were cancer and palliative care services developed in Lancaster 1976-2000?’ (See chapters 4-7). Having drawn chapters 2 and 3 together by showing that the methodology and method complemented each other, I will move on to explore the empirical chapters.

¹ Beier, L. (No date). Interview with Mr A4L for Family and Social Life in Barrow, Lancaster and Preston 1940-1970. The Elizabeth Roberts Archive. The Centre for North West Regional Studies. University of Lancaster.

² Beier, L. (1983). Interview with Dr A5L 1948-1983. The Elizabeth Roberts Archive. The Centre for North West Regional Studies. University of Lancaster.

³ McCaldin, M. (2010). Interview with Sara Denver in Stocksfeld on 9 September.

CHAPTER 4

FROM SCRATCH TO ROUTINE

4.1 Introduction

So far this thesis has given a broadly based review of the literature and key changes around cancer and palliative care services in the wider context when facilities began to emerge in Lancaster (see chapter 1). Chapter 2 dealt with methodology and chapter 3 addressed method, study design and analysis. This chapter is the first of three empirical chapters which explore the local 'microclimate' (by that is meant the 'individual' experiences and fine grained detail of the approaches/policy/practices that developed). Its key aim is to provide an overarching picture of how *tripartite* cancer and palliative care services developed in Lancaster and changed in the course of time. It starts by exploring the cancer support services to show how they evolved and expanded. Thereafter, it looks at the emergence and development of hospice and palliative care facilities. In addition, it establishes how the participants felt about being involved in these organizations from the beginning. The chapter also investigates the professionalization of these services first by scrutinizing cancer services, and then by looking at the hospice and palliative care facilities. It will go some way to addressing aims 1, 3 and 4 of my study:

- Aim 1: To ascertain how individuals developed cancer and palliative care services in one community.
- Aim 3: To place the research findings about service development in the wider context of cancer and palliative care issues.
- Aim 4: To increase understandings about the development of cancer and end of life care provision over time.

I achieved this by interpreting issues that were important and explaining how they fit into the change over time.

4.1.1 New creations

Cancer support services

There are three main points in this section, the first establishes when the idea for cancer support services began, the second examines the reasons why services evolved and the third looks at how they developed and the type of service offered. The reason for discussing these points is to uncover how cancer support services developed and to begin to address the first and fourth aims of the study (see 4.1).

The idea for developing cancer services in Lancaster began in 1978 following the appointment of Malcolm McIllmurray a ‘...physician with an interest in oncology’ (McIllmurray, Gorst and Holdcroft, 1986, p.669). A number of local clinicians were concerned about the paucity of specialist cancer facilities (McIllmurray, 2010)¹. Part of the remit was to ‘...create local cancer treatments and reviews at the Royal Lancaster Infirmary’ (Youren, 1996, p.1). It was a pioneering role because there were only two other similar posts in the country, and following Malcolm McIllmurray’s appointment steps were soon taken to set up cancer and palliative care facilities (Lovett-Horn, 1987). Yet it was unusual for an oncologist to have an interest in palliative care at that time (Bennett, et al., 1996) (see 4.3 and chapter 1). This suggests from the outset that ideas had a tendency towards the development of comprehensive services, yet that was not necessarily apparent to those involved at the time (McIllmurray, Gorst and Holdcroft, 1986; Parker, no date²; Youren, 1996).

There were four key reasons identified as to why the services developed. First, there was an increase in an awareness of the incidence and prevalence of cancer coupled with the development of new forms of treatment. In the district there were about 800 new cancer cases and 550 deaths caused by cancer each year, and these factors warranted the provision of ‘...special services’ (McIllmurray, 1987, p.117). Second, people became aware of the problems associated with accessing care in Manchester. Prior to 1978 there were ‘outreach’ clinics staffed by visiting oncologists from the Christie Hospital, Manchester but they only operated once a fortnight (McIllmurray, Gorst and Holdcroft, 1986; Youren, 2007). Local people were generally required to have chemotherapy at the Christie Hospital, which involved a journey around 140 miles or more for those living in the Lake District. Whilst geographically this might not be a long distance away, many of those in the

community reportedly suffered ‘...ghastly experiences’ (McIllmurray, 2010)³ especially if blood test results at the Christie confirmed that treatment on the day was contra-indicated and a wasted trip had been made. Similarly, if chemotherapy or radiotherapy was administered this often caused side effects such as tiredness and vomiting which were also problematic during the journey home (Youren, 2002). Many individuals encountered these negative experiences because they had to travel out of the district to access treatment. The lack of resources coupled with the journey was an ordeal for those who were unwell. Furthermore, the problem was compounded by a poorly developed public transport system. Many of those in the locality found this problematic and believed that if local services developed there would only be a need to travel to Manchester for radiotherapy or complex treatment. Pinch and Bijker (1984) argue that in the development of technology, a problem is only defined as such when there is a group for which it constitutes a dilemma (see chapter 2).

Third, it was also felt there was a need for local facilities because care was fragmented and there was no continuity, instead a spectrum of doctors were involved (McIllmurray, 2010)⁴. Consequently, care was not tailored to meet the requirements of individuals with cancer. When medical oncology started at the Royal Lancaster Infirmary those with cancer then had a special place for chemotherapy and attended an oncology clinic (McIllmurray, 1987). Links were soon formed with oncologists at the Christie Hospital for peer support and the sharing of information on protocols (McIllmurray, 2010)⁵. All of this suggests that local cancer services needed to improve the patient experience, quality of care and provide more comprehensive services.

Fourth, shortly after the medical oncology clinics began it became apparent to the proponents that a considerable amount of emotional distress had been hidden away. At the time it was not the culture to talk about cancer, and according to Youren (2002) many saw it as a ‘...death sentence’ (Youren, 2002, p.6). In the late 1970s early 1980s it was not conventional to provide psychosocial care, the general focus was on disease and its physical problems (McIllmurray, 1997) (see chapters 1 and 2). This does not mean that there were no concerns about illness, the side effects of cancer treatment or the anxieties associated with the diagnosis. However, this was for many at that time terminal and it impacted both on the person with cancer and their family. For example, a television programme ‘First Tuesday: A Silent Scream’ was broadcast to the nation around this time. It quoted the case of a young woman who told Malcolm McIllmurray about her fears of

chemotherapy, and he suggested trying supportive complementary therapy as a coping strategy (see chapter 5). The documentary also included another woman (in London) who provided a glimpse into the suppressed emotions surrounding cancer at that time:

‘...I felt devastated...Nobody...ever mentioned the word ‘cancer’...They treat the physical bits of your body which are being chopped off...then you are away from them and there’s another part of you that doesn’t get helped...at all – your emotions, the effect on your family...you just have to go home and cope with it...I had... ‘the horrors’...about midnight...I would lie in bed...crying but I wouldn’t be making any noise...strange to feel all the hot tears running down your face...inside...I was screaming but...it was silent...like a quiet scream’ (a young woman from London, cited by Quainton, no date, p.9).

This suggested there was a need for supportive care because there was a sense of desolation, abandonment and anguish. A lack of information and emotional support possibly impacted to intensify the fear. Moreover, these kinds of experiences prompted the proponents to challenge the rationality of conventional approaches and search for different ways to provide care. For example, Malcolm McIllmurray formed a view that individuals might benefit from talking about their emotions to an experienced nurse, either in the clinic or at home. He set about trying to find someone with the empathetic qualities that a Cancer Support Nurse would need.

Four notable factors were found to have been instrumental in shaping the development of cancer support services and the type of care provided. First, in 1981 ‘...a pilot scheme was instigated to investigate the effectiveness in improving...follow-up, by the appointment of a Health Visitor’ (Holdcroft, no date, p.1)⁶. Subsequently Pippa Youren (nee Holdcroft) was appointed as the first part-time Cancer Support Nurse to assist individuals and their relatives:

- With the initial acceptance and understanding of the condition.
- With the acceptance and maintenance of chemotherapy.
- To help solve the physical and psychological problems to be faced, including when active treatment was stopped.
- To cope with terminal care and bereavement.

Later that same year (1981) a medical student from the University of Manchester carried out an evaluation of the pilot scheme. The medical student reported that the Cancer Support Nurse enhanced care because she ‘...gathers information about patients, relatives and their problems...coordinates the provision of support services: and...is a counsellor’ (Holdcroft, 1984). The findings were used to secure funding which enabled the Cancer Support Nurse to work full time.

Second, the Consultant and the Cancer Support Nurse ‘...appear to have shared in the shaping of a vision, or a philosophy, about meeting the needs of patients and families...which extended far beyond a commitment to delivering the best quality medical treatment’ (Soothill and Thomas, 1998, p.70). The personality of the Cancer Support Nurse seems to have been particularly significant in shaping the services. Pippa Youren’s notes recording her thoughts on developing district cancer support services reveal something of her personality and philosophy (see discussion at chapter 5). For example, she aimed to ‘...acknowledge the uniqueness of each human being and create an environment that would encourage personal growth...empower people by giving them accurate information...experiment with...creative activities...enable us all to find some significance and meaning in our lives...’ (Youren, no date)⁷. The Cancer Support Nurse also found that as the facilities evolved it was possible to integrate hospital and community services and provide support during chronic illness or toxic treatment (Holdcroft, 1984). Holdcroft (1984) assessed the problems, identified needs and mobilized maximum support from the multidisciplinary team. The provision of timely information enabled individuals to be autonomous and participate in decisions about their care; many said how valuable this was (McIllmurray, 2010⁸; Youren, 2010⁹) (see chapter 5). This ‘patient centred’ approach differed significantly from conventional practices which did not generally include individuals in decision making, and patients were expected to fit in with hospital routines (Shepherd, 2007) (see chapter 1). The Cancer Support Nurse also had more autonomy than nurses had traditionally experienced because the consultant encouraged creativity and innovation (McCann, 2010¹⁰; McIllmurray, 2010¹¹). Soothill and Thomas (1998) found that this enabled ideas to emerge from the nurse and ‘take root’. For example, the nurse visited individuals at home because she realized that was where they would probably be more relaxed and able to talk about concerns, than they would in a busy clinic (Trotter et al., 1981; Winslow, 2009). The philosophy of the Cancer Support Nurse involved treating the physical, emotional and spiritual needs of individuals (Holdcroft, 1990)¹². There was a willingness on the part of those involved to listen to individuals/their families, and attempt

to understand what was needed (see chapter 5). The method resonated with Cicely Saunders' work that described the importance of caring 'about' patients not just 'for' them, and this involved listening in order to learn about needs (Saunders, 1965). It was also similar in its approach to the cancer support offered in Glasgow, evidence there had emerged which suggested that patients with cancer suffered high levels of psychological stress (Trotter et al., 1981). In addition, the health visitor was seen to have played an important role in offering care that addressed wider issues such as social needs, and she also provided a link between the hospital and community. These connections between the local and wider setting began to address the third aim of my study – 'to place the research findings on cancer and palliative care services in the wider context of cancer and palliative care issues' (see 4.1).

Third, it appeared to proponents of the cancer support service that as there was no facility in place it made it easier to develop one from scratch:

“...there were a lot of things about Lancaster that made life; (silence)...easier ...One of the things is that there was nothing at all. If you go into an area trying to set something up and there are already a lot of people...doing their...thing, it can be difficult...when you walk into a desert, all you need's a bit of water...Marvellous how it'll all come to bloom (Youren, 2010)¹³.

A paradigm shift then was not required to bring about change as the pioneers were not altering existing services. Nonetheless, there was tension at times because it was a different way of working compared to conventional approaches, and there was a need to change attitudes (Youren, 2010)¹⁴ (see chapter 6). There were many individual and social mechanisms operating to generate support for the new services. For example, the proponents were charismatic, they networked and had the contacts that were necessary to confront the social and medical restrictions of the day (see chapters 1, 5 and 6).

Fourth, the services were also developing in response to an increasingly questioning public which was beginning to express anger over poor treatment, lack of emotional care and the paucity of services (Quainton, no date; Youren, 2010¹⁵) (see chapters 1 and 6). Similarly there was a '...growing militancy...about the lack of information...' (Youren, undated, p.5)¹⁶ for those with cancer which increased the pressure for change.

The services then developed partly as a result of individual factors, the lack of strategy and also in response to a public that was becoming more socially influential. Small (2003) argues that change occurs when there are stories that produce pressure, politics decides if the pressure is bearable and the context decides the shape of response to that pressure. These components were evident in the oral history illustrations and consequently the cancer support service developed as a response to meet emotional needs. All of these examples taken together go some way to informing us about how the cancer support facilities started and what role the Cancer Support Nurse played in shaping them. I will now build on this evidence to explain more about the type of service offered.

Services included support for relatives

Pippa Youren had a great influence on the development of cancer services in Lancaster and one particular area she developed was support for patients. By 1982 she had formed a view that there was a need for a Relatives Support Group because there was little point in supporting an individual if the family were not included; they also needed to talk about concerns and identify ways in which they might be helped (Youren, no date)¹⁷.

Consequently, this development gave family members an opportunity to discuss concerns with relatives of other families and 'professionals' in an informal setting. It was unusual because the impact of illness on the family was not generally taken into account. Although in hospice care, Cicely Saunders understood the value of including the family in planning care (Saunders, 1965).

Initially the Relatives Support Group met once a month and then fortnightly at Ryelands House in Lancaster, which was provided gratis by the City Council¹⁸. That was important 'everything had to be free' because the group did not have any money, and the consultant and Cancer Support Nurse attended 'in their own time' (Holdcroft, No Date¹⁹; Youren, 2010²⁰). Participants did not know what to expect or whether anyone would attend, but a few people did and gradually more joined. It was a flexible affair where people chatted over coffee and could have a massage from a trained therapist (McIllmurray and Holdcroft, 1993). Initially those with cancer were not invited because they discussed any concerns with the Cancer Support Nurse. However, relatives soon reported that the person with cancer wanted to join in and so the group began to grow (McIllmurray, 1997). These informal developments were similar to those at cancer support organizations elsewhere, such as CancerLink and Bacup in London and Tak Tent in Glasgow (McArdle et al., 1996)

(see chapter 1). By attending the Relatives Support Group ‘professionals’ learned much more about the distress and misery individuals experienced. I found corroborative evidence in local documentary sources:

‘...I...curled up inside at the mere mention of cancer, having lost every member of my family with what I used to call the ‘dreaded lurgy’...you can imagine...the desolation I felt after losing my husband. I felt...abandoned in a place where no one cared...the...monthly meeting...I now find it a lifeline...’ (Saint, 1986, p.11, reflecting on the Relatives Support Group²¹; Cited by Youren, 2007, p.27).

The recognition of psychological distress as a key problem among those with cancer and their relatives was used to strengthen the argument that there was a need for the development of support services. There is substantial evidence to point to the support group being a positive feature because it offered a chance to talk, and this helped individuals cope with their situation. However, some might not have wanted to discuss anxieties and would not have been interested in attending a support group (Howarth, 2010)²². Particularly in a culture which appeared stoical, some were perhaps more comfortable ‘putting on a brave face’ (see chapters 5 and 6). On the other hand they would not know of the potential benefit unless they tried it, so at least by offering supportive services people were made aware that they were available if needed at a later stage.

Expanding the support services

Following Pippa Youren’s appointment as a Cancer Support Nurse three key innovations were identified as expanding the cancer support facilities. First, support nurses Roberta Whiteside and Ellie Maguire were soon assigned to extend the services to Morecambe and Kendal (about a half hour’s drive from Lancaster). Second, in addition to the need for general cancer services there was also a specific need for breast cancer support following surgery. In 1983 Health Visitor Elspeth Hopkins was on a routine visit to a child in Morecambe, a serendipitous encounter with the child’s mother revealed that she had recently undergone a mastectomy. At the time unless chemotherapy was recommended women were not referred to oncology or the cancer support facilities, and Elspeth Hopkins formed an impression that services were ‘totally lacking’ (Hopkins, 2010)²³. The experience inspired her to take strategic action in the form of a breast care support group, which she ran voluntarily for two years. During this time she ‘banged on the door’ of

professionals to introduce herself and the voluntary service, ‘nobody actually said no’ to her suggestions. That was taken ‘as a positive’ and like the cancer support group, the breast support group met at Ryelands House once a month (Hopkins, 2010)²⁴. Third, around this time Malcolm McIllmurray contemplated whether there might be other useful approaches such as ‘relaxation therapy’, to reduce stress and help meet psychological needs. He approached Meg McCaldin, whom he had met several years earlier when his wife attended her childbirth classes at the National Childbirth Trust (Youren, No Date). Having seen the benefits of ‘relaxation therapy’ in other settings, Malcolm McIllmurray was inspired to suggest it as a complementary therapy:

“Malcolm...asked me if I would be interested in doing some relaxation work with cancer patients...and their families...would be about 1983...they were just setting...CancerCare up...I said...I’ll try...on the understanding that people know that it’s experimental and...I shall have to try and develop something with the feedback I get...it can be with individuals or they can bring partners...we’ll just literally play it by ear...see how it develops” (McCaldin, 2010)²⁵.

There was clearly a willingness to ‘find other ways’ to care for those with emotional needs. Yet at that time it was uncommon for doctors to have an interest in complementary therapy (Nicolson and McLaughlin, 1987) (see chapter 1). The actions of those in the area meant that for many emotional care became important, psychological problems were seen to be as ‘real’ as physical problems and there was a change towards the provision of holistic care. In developing these ideas people drew from a range of different sources. For example, in extending the learning from childbirth relaxation classes to individuals with cancer, proponents were breaking new ground as there was a shift from care that advantaged mechanistic approaches (Kearney, 1992). Moreover, emotional issues were now seen as ‘real’ problems, and the next section explores how the proponents began to spread this important message to a broader group in an attempt to further develop cancer support services.

4.1.2 Spreading the word; wider contextual influences

The proponents of the cancer support services began to take their ideas to a wider audience in three significant ways. First, in 1984 the cancer support group registered as the charity ‘CancerCare’. It was an important organizational consolidation because it resulted in

‘...bringing representatives from our community together onto the Advisory Group...’ (Youren, 2007, p.4). Voluntary representatives were from wide backgrounds and included consultants, general practitioners, nurses, a social worker, a member of Lancaster City Council, a solicitor, a member of the Community Health Council and a journalist. The idea behind the invitation was to provide members with updates, so they could let colleagues know what was happening within CancerCare and hopefully refer families for support (Youren, 2007). The relationship between this and the cancer and palliative care services that eventually evolved was that these developments required collaboration. Those in the cancer support services created links with individuals in key positions in the community/hospital, who could spread the word about the support work to those in their own areas. It was an opportunity to bring different people and organizations together, and in turn this created further connections for the cancer support services.

Second, the scope of complementary therapies on offer was widened to include yoga, hypnosis and counselling, they were carefully controlled so that the ‘best’ perceived therapy was provided. Third, Malcolm McIlmurray and Pippa Youren began to share ideas with those in the broader arena. National conferences were organised to inform others about the local services (McCaldin, 2010)²⁶. It attracted national and international professionals who were interested in the local cancer and palliative care services. The first Annual Lecture was delivered by writer Dr Michael O’Donnell in 1984; in 1986 the Bi-Annual National Conferences started with talks by significant international experts such as oncologist Dr Rob Buckman and psychiatrist Dr Peter Maguire:

“Peter Maguire and Rob Buckman were doing the...weekend lecture at the University and they were our main speakers...bringing Rob Buckman over from Canada, I mean cor big time...” (Youren, 2010)²⁷.

One of the Conference themes was about ‘breaking bad news’ another related to ‘improving the quality of care’ of cancer patients (Youren, 2007, p.53). It further supports the argument that perspectives widened to include the emotional and social implications of a cancer diagnosis, instead of just concentrating on the biomedical aspects of oncology. Furthermore high calibre, impressive experts lectured at the conferences and this probably increased the reputation of the local organization and its practice.

There were two factors detected in the wider context that also served to shape local developments. First, links forged with organizations such as CancerLink and Backup in London led to greater collaboration and sharing of experiences/information. Second, in 1979 The Bristol Cancer Help Centre provided care that centred on the whole person, and offered holistic care to those that had been told elsewhere there was nothing that could be done for them. The philosophy appealed to those developing services in Lancaster:

“...the Bristol Cancer Help Centre...was a big influence...was a...wee bit extreme...at least people listened to patients, people cared about the whole family...treated them like human beings facing probably the greatest crisis of their life...facing life and death issues...” (Youren, 2010)²⁸.

Holistic practices in Bristol influenced the local cancer support services and a similar approach was followed. Yet they differed in relation to the therapies offered because ‘alternative’ therapy at Bristol attracted profound medical scepticism (Bagenal et al., 1990; Chilvers et al., 1990). Pippa Youren also formed a view that Bristol was a bit extreme in respect of therapies such as ‘...coffee enemas for relief of pain and use of ‘the Bristol Diet’, which was a type of vegan regime’ (Youren, no date, p.5)²⁹. The controversy peaked in 1986 following an evaluation study of women with breast cancer undergoing complementary therapy at Bristol:

“...a lot of the people who went to Bristol were people who had no hope, had been told there’s nothing else we can do for you...that was one of the problems about the research that was carried out...the eminent consultant who was heading the team who carried out this research...eventually committed suicide...” (Youren, 2010)³⁰.

The research concluded that Bristol ‘...women...fare worse than those receiving conventional treatment only...’ (Chilvers et al., 1990, p.609) because there was evidence of poorer survival rates, the researchers held a press conference to report their findings (Rattigan, no date, p.8). Yet not long after publication questions were raised about the reports authenticity, weakness in design and statistical interpretation (Hayes et al., 1990). Further scrutiny revealed that no one had ensured the control group avoided complementary therapies; additionally lifestyle, relationship and environmental factors were not taken into consideration. Consequently, the impression was there were little differences between the prognostic features of ‘cases’ and ‘controls’, but this was not the

case because 42% of the Bristol women already had metastatic disease and a worse prognosis (Hayes et al., 1990). The Bristol Cancer Centre impacted on local progress in Lancaster in both beneficial and adverse ways. For example, the holistic nature of care had positive ramifications on local developments because it appealed to the philosophy of local individuals who created cancer support services. From a critical perspective if a higher number of people in the terminal stages went to Bristol because they had been told nothing could be done, they might literally have been willing to try anything for the prospect of some extra time however slim that possibility was. Nevertheless, the upshot of the polemical situation there made it extremely important to vet therapists carefully in Lancaster. Moreover, it was important to offer a 'complementary' rather than 'alternative' service because it had to be seen as credible by local colleagues, and those in the wider field (McIllmurray, 2010)³¹. All of these illustrations confirm that broader social and professional mechanisms impacted to shape local services as they developed and expanded.

4.2 Cancer support: paths and developments

The cancer support service in Lancaster continued to develop and a number of important innovations unfolded. First, the range of complementary therapy broadened further as it was seen to benefit those who used it. In addition to massage, relaxation, hypnotherapy and crafts there began to unfold other approaches such as art, patchwork and quilting:

'...my husband had been diagnosed with terminal cancer...my one aim was to look after him at home...I desperately needed some stimulus outside the home to give a new focus to my necessarily restricted life...Netta maintained our classes should aim high...stimulate, inspire...give...us a feeling of satisfaction and self-worth...During the dark days of my husband's final illness, I was able to find some solace in my craftwork...with a needle in my hand I could sit quietly by his bed and carry on working with a purpose...Afterwards I found the support of the group of immeasurable help' (Harris, no date, p.3).

This account intimates that craft like patchwork was valued because it gave people a sense of worth and meaning to their lives which helped them cope. It was particularly beneficial to those caring for a dying relative at home because it provided some diversion. During exceedingly difficult times individuals could turn to crafts and experience a sense of

‘control’, when they perhaps had little command over their relative’s illness. Similarly, administrator Jan Howarth explained that there were perceived benefits of other forms of complementary therapies, yet there were also differing perspectives:

“...it was the early days of Cancer Care...massage at the hospice with Lizzie Watson...coming here I just thought what a wonderful place...but it's not for everybody, not everybody with breast cancer wants to come to the breast care group” (Howarth, 2010)³².

It was important not to ‘assume’ the cancer support service would benefit everybody because there were cultural reasons why some people did not welcome it. Nonetheless, others found there were advantages to be derived from the supportive care. Second, the facilities expanded further when Ellie Maguire started a ‘drop-in’ service run by volunteers in Kendal:

“...I didn’t go to the clinics, and that’s what made us look at...some form of place that they could come...to let off a bit of steam...or share their fears...that’s when we started to think about a drop-in...” (Maguire, 2010)³³.

The drop-in service enabled individuals to meet, discuss anxieties and obtain support in an informal, friendly environment. Susie Roth, volunteer and later Matron of St John’s Hospice confirmed that the service was highly valued by the community because people were often very anxious when they had just had a cancer diagnosis and needed to talk about how it would impact on their life (Roth, 2010)³⁴. Subsequently, the drop-in grew rapidly from its humble start in a small room to eventually taking over the whole of Kirkland Hall, Kendal. This was much more than a ‘coffee morning’. For example, it provided informal yet ‘professional’ assistance, support and information. It allowed the timely discussion of problems and there was no longer a need to save anxieties for the next oncology clinic; these could be offloaded at the flexible drop-in. It was very popular and its success led to drop-ins expanding in Lancaster, Morecambe, Ambleside and Windermere. The illustrations clarify that the cancer support services were valuable to those who used them and to the volunteers within. Third, cancer services expanded further in 1986 when Ward 3 Annex at the Royal Lancaster Infirmary became the first local in-patient unit for cancer patients, Millie Shepherd was appointed as the initial Oncology Sister to provide chemotherapy (McIllmurray, no date³⁵; Youren, 2007). Fourth, similar changes got

underway in Kendal as Jan Hunt Medical Ward Sister developed oncology services with Malcolm McIlmurray, yet this was not until 1993. Then the people of South Cumbria had access to local services and not long after palliative care was made available (Hunt, 1993). This gives further impetus to the argument of this thesis that care developed comprehensively because palliative care was also recognised as important (Hunt, 2010)³⁶. Fifth, by 1986 CancerCare was based at St John's Hospice (see 4.3), the range of complementary therapies and art/craft classes at the social day care grew to such an extent that by 1989 it needed its own premises³⁷ (CancerCare Slynedales Appeal, 1989). A derelict house owned by the City Council situated next door to the hospice in Lancaster came up for auction. An appeal generated sufficient funds to buy it for the remarkable sum of £295,000 and it became known as 'Slynedales' (McIlmurray, 2010)³⁸. It was a large, detached property surrounded by a mature garden of considerable size. Ken Youren volunteer and husband of Pippa Youren explained that the cancer support services were able to expand in this way because there was a great deal of community spirit and volunteers who had the time to renovate Slynedales:

“...I was at a loose end...I used to go up in the mornings and get the thing rolling, because it was in such a terrible mess. It had been neglected, left empty for 3 years...we got the carpet from Marks & Spencer's...nurses, doctors, and everybody chipped in...scouts...people...on community service” (Youren, 2010)³⁹.

Consequently Slynedales became the home of CancerCare it provided education, information, therapies and the social activities I have explored (McIlmurray and Holdcroft, 1993). Considerable interest was generated in the wider framework over these local developments. For example, the Association of Cancer Physicians was keen to look at the future development of district cancer services and approached Malcolm McIlmurray with a view to putting a document together about the Lancaster services (McIlmurray, 1997). Moreover, the report of the Working Group of the Association of Cancer Physicians was published in the prestigious *Journal of the Royal College of Physicians* (McIlmurray, 1987). It called for an increase in oncology posts and services at district level, it espoused the benefits of cancer support nurses and advocated that they should be made available nationwide. Accordingly, this signified an important change because nurses now had the potential to be more autonomous if doctors at district level followed Lancaster and facilitated similar appointments (see chapter 1). There is no doubt that local services generated interest from wider professional bodies and had some influence on early policy

in the wider field. All of these accounts revealed that cancer support services developed out of a perceived need for holistic care. Documentary sources containing reflections from individuals and relatives supported these oral histories. Moreover, the accounts show just how flexible services were in the early stages of development, and this links to the first stage of the EPOR when interpretative flexibility of scientific findings is displayed (Pinch and Bijker, 1984). The actors and approaches of the cancer care services were malleable because of differing forms of rationality. For example, the protagonist's practices were very flexible and they were open to a wide range of multidisciplinary ideas. Furthermore, connections can now be made with the central argument of this thesis that care developed comprehensively because there was flexibility to enable services to stretch to include palliative care. There were individual, social and economic mechanisms that impacted to make this possible. For example, those involved in setting up the support services succeeded in gaining funding from the community, they recruited volunteers and the number of people needing care was relatively small. I have also shown that there were broader social, historical and professional factors operating to influence the cancer services. I will move on now to explore the hospice developments.

4.3 Creation of St John's Hospice

There is a degree of overlap between the evolution of the local cancer support services that I have described, and the development of hospice/palliative care services because some individuals were connected to all the organizations. I will discuss the early developments, hospice services and influences in the broader arena.

Early developments

It all began around 1976 when some local individuals including Lucy Parker a social worker and Bill Hay a physician formed a view that there was a need for an inpatient hospice in the Lancaster area (McIllmurray, 1997). That year a meeting took place at Thwaite Gate House, Carnforth the home of Lucy Parker and a Committee was formed to discuss the possibilities⁴⁰. However, the Committee could not see a way of generating the revenue that was needed, so plans did not progress at that time. There was a hospital out at Silverdale about a half hour's drive from Lancaster called St John of God Hospital, which was owned and staffed by the Sisters of Our Lady of Apostles. The Sisters had an agreement with the Area Health Authority to provide services in return for payment; Lucy

Parker was connected to the Hospital through her social work. St John of God had a mixture of patients ranging from orthopaedic convalescence to long-term care, and it had also started to provide some terminal care. Mike Warren, a General Practitioner was affiliated to the Hospital because he provided medical services (which he continued at St John's Hospice when it opened). He explained how serendipity led to the start of in-patient terminal care:

“...one day a chap...rang me...urologist... he said, ‘I’ve got a chap with cancer...there’s nothing we can do for him, he’s dying...will you take him?’...He didn’t know what to do so he thought, ‘I know somewhere that might be able to deal with it.’...I didn’t know what to do either, but I say yes...we took this chap...it was really quite successful. He died there having had it explained...he was at the end of the road...he accepted it because I think he was so ill that he realized...Having done that once, we thought this was perhaps something that needed doing...over the period to...the mid 1980s this gradually grew to the extent that we had eight beds...dedicated to terminal care” (Warren, 2010)⁴¹.

There were signs then of palliative care starting to develop as early as 1976. Janet Corkill, volunteer at St John of God (later administrator at St John's Hospice) corroborated this and added that by 1983 individuals were nursed until they died so “...it was like a little beginning of the hospice” (Corkill, 2010)⁴². Shortly after Malcolm McIlmurray had arrived in Lancaster he met Lucy Parker and learned that she had started referring terminally ill cancer patients to St John of God Hospital, they were both of the view that there was a need for a place to care for the dying (McIlmurray, 2010)⁴³. Saunders (2000) argued that doctors generally deserted the dying, yet in the local area there was an interest and the prospect of converting St John of God into a hospice was considered. It was dismissed as being too expensive when it emerged that it needed re-roofing and renovating in order to meet health and safety standards (McIlmurray, 1997).

Four key events were found to have connected in succession to facilitate progress. First, a Steering Committee was appointed to investigate the possibility of raising funds to build a hospice in the region. As part of these investigations enquiries were made as to how hospices had evolved elsewhere, and there was some indication that developments in other places impacted on the decision to build a hospice in Lancaster. For example, Lucy Parker visited St Ann's Hospice, Manchester and after seeing the work achieved decided a local

hospice would be a good thing (Warren, 2010)⁴⁴. Similarly, Sister Aine and Lucy Parker visited the Holy Cross Hospice in Hazlemere to get some ideas⁴⁵; links were also forged with St. Christopher's Association of Hospice Administrators when Malcolm McIlmurray was nominated as a member⁴⁶. After much discussion Lancaster was considered the best place to have a hospice because it had the greatest population, along with National Health Service facilities⁴⁷. Second, a decision was made to approach the Area Health Authority to see whether the contractual arrangement with St John of God could be transferred to a new hospice, if funds were raised in other ways to build it. Third, it was proposed that St John of God would close, the Order would move to the new hospice when it was built with Sister Aine Cox from St John of God Hospital as Matron. It was felt that there was a need to provide facilities for the terminally ill, as well as those who were 'chronically physically handicapped'⁴⁸ because they lived at St John of God and would need to be re-homed when it closed. The project was not confined to patients with cancer but included those '...suffering from chronic disabling diseases' (The North Lancashire and Lakeland Continuing Care Trust, no date, p.5). Therefore, it was not typical of hospices because most provided care to people with cancer (Murtagh, Preston and Higginson, 2004). Fourth, funding was secured to make the project a reality:

"...we...went to the Health Authority and said...we'd like to...provide a purpose built unit for terminally ill patients...if we were able to do that would they be willing to transfer the costs related to the contract...with St John of God Hospital to the new unit...we reached agreement...this arrangement fitted perfectly...we got the Trust together and we got the original Trust Deed" (McIlmurray, 2010)⁴⁹.

The Operational Planning Committee for the North Lancashire and Lakeland Continuing Care Trust secured funding for the 'running costs' of a new hospice, provided sufficient money was raised to build it. Rodney Ward, Trustee corroborated this arrangement (Ward, 2010)⁵⁰ and following a meeting on 6 February 1980 an assurance was given that:

"...the running costs of the new unit were not seen as a problem being a substitution and development of the funds now incurred in the costs of St. John of God and a contractual arrangement...would therefore continue"⁵¹.

It was a remarkable achievement and fundraising plans could go ahead to build a hospice in Lancaster. The name – North Lancashire and South Lakeland Continuing Care Trust

was an interesting choice because ‘Continuing Care’ was used by the National Health Service to describe their hospice units (Doyle, 2005) (see chapter 1). Perhaps there was hope locally that the hospice would eventually come within the National Health Service. Nevertheless, the hospice originated as an independent charity because it had not been possible to secure sufficient funding from mainstream sources to build it, and this was typical of hospices at that time (James and Field, 1992; Parker, no date⁵²). Moreover, local hospice development was facilitated by the Nuns who had a contract for ‘operational’ funding, and were amenable to closing St John of God Hospital and transferring the arrangement to a new hospice. The ‘Shadow’ Trustees met on 6 May 1980, as the running costs could be met⁵³ they signed the North Lancashire and Lakeland Continuing Care Trust Deed⁵⁴, and the Charity Commissioners registered the Trust. Trustees agreed to send formal notification to the Area Health Authority so that it could be noted in the Minutes, and its successor would be committed to financing the ‘revenue consequences’ of the project⁵⁵.

Although the hospice developed outside the National Health Service there was a contractual commitment to funding the running costs. Nonetheless, it was subject to the proviso that the North Lancashire and Lakeland Continuing Care Trust raised the money to pay for the building. Therefore an appeal was launched to raise the capital needed for the building; the estate of the Rt. Honourable Josephine Countess of Sefton and the Multiple Sclerosis Society provided major donations⁵⁶ (Barnes, 1981; The North Lancashire and Lakeland Continuing Care Trust, no date). Considerable community spirit was generated by ‘Friends of the Hospice’ who started collections for the building project (Ward, 2010)⁵⁷. In addition, Trustees recognised there was also a need for a hospice ‘...community service’, that would care for those who preferred ‘...to die at home’ (The North Lancashire and Lakeland Continuing Care Trust, no date, p.12; ⁵⁸). Yet when they outlined the concept of a domiciliary nursing team to supplement district services it was not welcomed by this general practitioner who:

“...expressed his concern that the present service which he considered to be excellent would become disjointed if the full management of the patient was not under the oversight of the general practitioner”⁵⁹.

There was then some dissent over the introduction of the proposed hospice at home service (hospice nursing service provided at home). It intimates that tension was related to

who would have overall authority and some were not prepared to release control, which was a common feature in hospice history (Clark et al., 2005) (see chapter 6). If the hospice that eventually evolved by 2000 was taken as 'evidence of its success', it would miss the opportunity to show that by studying developments over time, the direction taken was probably not the only one that could have been forged (as Pinch and Bijker, 1984 found in the development of technology). By applying Pinch and Bijker's multidirectional model on the SCOT it becomes apparent what impact broader factors might have had on the way services evolved (see chapter 2). Plans for hospice at home services did not advance at the time because of wider professional and social conditions. From a critical viewpoint General Practitioners provided 24-hour care at that time and needed to be up to date with a person's condition in case they were called in the night.

Soon plans were being discussed as to how to transfer individuals from St John of God to the hospice. At the First Operational Planning Committee discussion centred on the concept of 'Continuing Care', which originated from the need to care for the terminally ill and the '...chronically physically handicapped and how this linked in with the replacement of St. John of God...' ⁶⁰. Primarily the plan was to transfer some patients to the hospice for 'long-term care'; others would be admitted for short periods of respite. Geriatric and orthopaedic cases previously admitted to St. John of God would be accommodated within the National Health Service. The relationship between this and the development of comprehensive services was that these were not just cancer services, but included those with chronic physical conditions and multiple sclerosis. Furthermore, there was evidence of collaboration with the mainstream resources and this facilitated the 'comprehensive' services.

The intention was to design a 34-bedded hospice; St. John of God Hospital had about 60 beds so in comparison a 34-bedded hospice might not have appeared too large. Yet on reflection it was seen by some as a high number of beds for the size of the community, as Margaret Ellam (the first Consultant to develop specialist palliative care at the hospice at a later time) explained (Ellam, 2010) ⁶¹. A decision was made to use land in the Skerton area of Lancaster to build the hospice because the Area Health Authority had undertaken to provide it, the location was determined by its availability rather than other factors (Ward, 2010) ⁶². In June 1982 negotiations resulted in:

“...the City Council giving approval for a building licence for the Trust which stipulated that given building regulations approval, full planning permission and the laying of foundations within 12 months that following this period conveyance of the land for £66,000 would proceed”⁶³.

By 23 November 1982 the contract was ready to sign, payment was due and the Trustees agreed to proceed⁶⁴. Building work had been put out to tender and it was estimated at £802,500 with 12% of this figure for professional fees⁶⁵, costs then escalated to £1,200,000⁶⁶ and by 1984 had reached £1,928,711.23⁶⁷. Moreover work was behind schedule; the original completion date was 31 July 1985⁶⁸ and the final cost came in at £2,000,000⁶⁹. On 1 November 1985 the keys were handed over⁷⁰ and the first patients were admitted on 5 December 1985, although the Duchess of Norfolk did not perform the ‘official opening’ until 8 January 1986. The new hospice needed a name and after much debate ‘St John’s’ was considered most appropriate because it had historical links with St John of God, and the Nuns from there would transfer to the new hospice (Ward, 2010)^{71 72}. A Board of Management comprising certain Trustees was now required to ensure objectives were met⁷³, and the Management Committee administered the hospice on behalf of the Trustees. Shortly after opening however it emerged that the new location did not suit everyone:

“...when the...hospital shut down they asked me if I’d like to come to the new hospice...all the domestic staff...kitchen staff and the laundry staff...left quite soon...Because they tended not to have cars and not to really want to travel into Lancaster. They lived in Silverdale or Carnforth...the other nurses would pick them up... but it wasn’t very satisfactory...when they were working shifts...they weren’t at the right times” (Corkill, 2010)⁷⁴.

The location was not convenient for the domestic staff because many lived rurally; they were also likely to have been less well off and did not have cars or access to good public transport. Consequently many of the kitchen, laundry and cleaning staff left shortly after the move because of these social factors. Yet the hospice was built in Lancaster because that was where the population was concentrated, and therefore it was more convenient for the majority living there (Parker, 1980)⁷⁵. It was interesting to reveal different perspectives and I think that this occurred because the oral history was underpinned by relativism. Therefore the methodology complemented the method and searched for multifarious

stories. Furthermore, by focusing on the accounts to interpret the meaning attached to experiences, I was able to link these with social factors (rural area, lack of transport and additional expenses) to reveal their impact on developments (Mallinson et al., 2003; Thompson, 1988) (see chapter 3). The next section focuses on the services provided by the hospice when it opened.

Hospice services

A key point about hospice services was that they were very flexible and informal in the early days. Some observers took the view that the hospice was less sophisticated because it had started from scratch, the purpose of care was mainly to meet social needs and only sometimes symptom requirements (Warren, 2010)⁷⁶. Initially there were few administrative staff and they did whatever tasks needed doing. At first the main focus was on the inpatient unit:

“To begin with...Everything was to do with the ward, the ward was the hospice...they started our little day care...It was very informal...the patients just knitted or something...it was run by...volunteers” (Corkill, 2010)⁷⁷.

The hospice was quite simple and informal and care was concentrated on those admitted to the ward. Gradually it began to reach a wider population and the main innovation identified as to the reason for this was the development of social day-care in 1989. The consequence of that change was that links were made with individuals in the community as they could attend the hospice in the day and then go home at night. Susie Bulman, Deputy Matron explained this had a significant impact on the way people saw the hospice change from a place that one would never leave, to one where people went home and then returned at a later time (Bulman, 2010)⁷⁸ (see chapter 6). Often volunteers became involved in the day care service because they had spare time:

“...I didn't work outside home...I just felt I had time to spare...with Margaret...I started day care...in 1989...” (Carne, 2010)⁷⁹.

Giving time to support hospice day care was important because there was little money and volunteers did not ‘cost’ anything. Yet they gave a level of commitment not a ‘one off’ act

of assistance, and similar characteristics featured in the wider context of hospice development (Hoad, 1991). Volunteer Pat Johnson who later became Transport Manager set up a transport service run by volunteers to ‘bus’ people in to day care; the advantage of this was that people did not have to organize transport and it became easier for them to access facilities (Johnson, 2010)⁸⁰. I will now look at the impact of wider factors on these hospice developments.

Influences in the broader arena

There were indications that leading pioneers in the hospice field had an impact on the way local terminal care developed. For example, Mike Warren went on several occasions to Cicely Saunders’ ‘Doctors’ Weeks’ at St Christopher’s. Similarly, training took place at St Luke’s in Sheffield founded by Eric Wilkes and St Columba’s Hospice in Edinburgh where Dr Derek Doyle worked (Warren, 2010)⁸¹ (see chapter 1). There was also evidence that the local hospice influenced terminal care in the broader field. By way of illustration, Sister Callistus of St John’s Hospice went to Russia to help start the first hospice there (Corkill, 2010)⁸². Yet there was little cooperation between local hospices in the early days, although this changed in time because greater collaboration was facilitated through Help the Hospices (Ward, 2010)⁸³.

This section has explored the history of local hospice developments and on a general point they were very flexible in the early stages like the first stage of the EPOR in the development of scientific knowledge (Pinch and Bijker, 1984). Such flexibility enabled those at the grassroots to create hospice facilities that provided care for those suffering chronic or terminal illness, disability or disease as well as cancer which was not customary of hospices at the time (see chapter 1). Furthermore, this approach links to the overarching story of the thesis that these services were developing in a comprehensive way (McIllmurray, Gorst and Holdcroft, 1986). I have also indicated that there were broader social, historical and political mechanisms operating to shape services. These illustrations and interpretations go some way to addressing the first and third aims of my study (see 4.1). Next I look at how it felt to be involved in the cancer and palliative care services from the beginning.

4.4 How it felt to be involved

There was substantial evidence to indicate that being involved in the development of the cancer and palliative care services that I have described was a positive encounter. This section explores how participants felt about being involved in these facilities by focusing on the meaning they attached to their experiences. Five factors were identified as making the experience a positive one - feeling special, shared vision, unconventional approach, a sense of community and rewarding experience; these are now discussed in more detail.

Feeling special

Many accounts revealed there was a sense that being involved in the cancer support services had been a 'special adventure', and it was partly because they were small:

“...there is something about small being beautiful...Those early days were very good...there were a comparatively small number of people involved...we were...able to offer what we wanted...virtually no constraints on us...we had the best of it...it was wonderful”(McCaldin, 2010)⁸⁴.

The flexible practices created a 'feel good factor' where individuals flourished because creativity was not restricted by regulations or costs, and participants felt that they were doing something worthwhile. According to Corkill (2010)⁸⁵ being involved in the hospice service was also beneficial to volunteers:

“...very exciting...I've enjoyed it...it's made a difference to my whole life...terrific...a real opportunity...the benefits that I've got...it's been good to be in something right from the beginning...you can see things changing” (Corkill, 2010)⁸⁶.

Involvement in a new project bestowed positive feelings of uniqueness and excitement. For others seeing people in remission was also a key reason why it was such a positive experience to be part of CancerCare (Howarth, 2010)⁸⁷. Being part of something special also equated to being successful, participants felt they had done a good job in developing the cancer support services (Youren, 2010)⁸⁸. Similarly, acquiring Slynedales for CancerCare was considered a tremendous *coup* resulting in a wonderful day centre

(McCaldin, 2010)⁸⁹. There was a sense of ‘team spirit’, nurses had more autonomy than many others elsewhere and the role was more satisfying (McCann, 2010)⁹⁰ (see chapter 5). In the broader field there was also a perception that the local services were part of something unique. For example, Gill Ormerod was a cancer advisor in Edinburgh before becoming a counsellor in Lancaster, and she explained that CancerCare was seen nationally as a special organization (Ormerod, 2010)⁹¹.

Shared vision

Numerous accounts unfolded about kindness and a shared vision:

“...we all had a dream...shared that dream...shared core values and belief...with this handful of people...once you lose that, you can’t recreate it really” (Youren, 2010)⁹².

Those involved at the beginning shared a common dream about how to provide care, it was possible to work towards mutual goals because the organizations were flexible and small (see chapter 5). Clark et al (2005) also found that having a shared dream to find a better way of caring was a common feature amongst the hospice pioneers (see chapter 1). Although many individuals worked extremely long hours they did not mind because they were all working towards the same outcome (McCaldin, 2010)⁹³. Everyone ‘pulled together’ to get Slynedales ready for CancerCare opening, this involved sharing tasks such as scrubbing floors and painting. It was this ‘group effort’ that helped to create a feeling of camaraderie (Johnson, 2010)⁹⁴. However, it was challenging as services grew because then the goals changed to reflect the experiences and views of additional people until eventually the original concepts were lost (Youren, 2010)⁹⁵ (see chapter 6).

Unconventional approach

There was a sense that the *tripartite* service with oncology, cancer support and palliative care facilities so closely linked was unusual (Warren, 2010)⁹⁶:

“Lancaster used to be quite unique...because we had got things going...that other places didn’t...a lot places were interested in how we had incorporated our

complementary therapies within the kind of medical setting...that's what made...ours a bit special..." (Youren, 2010)⁹⁷.

Offering complementary therapies within the medical setting of oncology and palliative care distinguished the *tripartite* services from other places (McCaldin, 2010⁹⁸; McIllmurray, 2010⁹⁹). I have identified that there is a gap in knowledge and until further research is conducted we do not know how cancer and palliative care services developed in other local settings (see Introduction, chapters 1 and 7).

A sense of 'community'

Jean Warren, volunteer explained that the hospice was also a 'community' in its own right because it was a place where volunteers, nurses, doctors and 'odd job' helpers socialized in a 'friendly atmosphere' (Warren, 2010)¹⁰⁰. This was a familiar trait in other areas (Clark et al., 2005) (see chapter 1). Similarly the drop-in service was like a 'big family', many of those involved were bereaved and made new friends because there were opportunities to socialize in the form of shopping excursions, Christmas parties, dinners, holidays and even marriages (Roth, 2010¹⁰¹; Youren, 2010¹⁰²). Geraldine McIllmurray, volunteer who was also married to Malcolm McIllmurray explained that overall these cancer and palliative care services enhanced the community because they were comprehensive:

"...both...projects have enriched the...community...and that is a very positive thing...an enormous success... and...they ran parallel...the hospice per se is not enough...you...need a real support network..." (McIllmurray, 2010)¹⁰³.

These illustrations intimate that additional social factors impacted on the development of *tripartite* services by bringing people together within a 'community'. Furthermore, the cancer and palliative care services then impacted on the community by providing support in a collaborative and comprehensive way.

Rewarding

Many participants formed a view that being part of something new was rewarding and a privilege because they were trusted (Maguire, 2010¹⁰⁴; Shepherd, 2010¹⁰⁵):

“...it was just such a privilege...to be able to reach out to talk about things that were otherwise unsayable...you got massive reward of course...for being trusted and being seen as alert...credible and attentive” (Ormerod, 2010)¹⁰⁶.

Gill Ormerod, former Counsellor illustrated that this privileged experience stemmed from being able to connect with individuals to create a level of trust in the first place. As a result individuals began to talk about death, dying and other issues previously hidden. This was also an act of reciprocity because in return there was huge personal reward for the counsellor. These accounts provided evidence suggesting encounters with both the cancer and palliative care services were beneficial, yet there was also evidence which was at variance to this which is explored next.

4.5 Differing experiences

There were some accounts that did not fit with the majority and it was important to have uncovered these because it enabled a multiplicity of viewpoints to be created (Thompson, 1988). David Hopkins, General Manager of CancerCare expanded on some of the positive and negative experiences of fundraising and the time that was devoted to the services:

“I would overhear bits of...conversation, like...I don’t know what I would have done...without CancerCare...very heart warming, but the other side...was...you were often out on social hours talking to groups...it was very hard to draw boundaries...volunteers...pestering you...the first person they came for a quid was me...and...the emotional aggravation...for what you were trying to do...was actually a very high order...I found myself losing sleep over some of these issues” (Hopkins, 2010)¹⁰⁷.

Those providing the services had to do a lot of fundraising in their own time; they often gave evening talks to generate financial support which could be frustrating. The majority of participant’s portrayed experiences which indicated that complementary therapy was valuable, however others could not see its advantages (McKinney, 2010)¹⁰⁸ (see chapter 6). There was tension at times over the allocation of funds for complementary therapy when emotional care was not seen to be as worthy as conventional clinical approaches (Addington-Hall et al., 1993; McIllmurray and Holdcroft, 1993). On a critical point the cancer support organization was independent and responsible for generating funding. I

have explained that there was the initial fund raising appeal to purchase Slynedales. Once it was operational events were also organized by all sections of the community to fund the cancer support activities (CancerCare Slynedales Appeal, 1989; Youren, 2007). Having explored the proponent's experiences of starting the cancer support and palliative care facilities from scratch the next section explains the change as the services expanded.

4.6 Professionalization of cancer support services

The cancer support services in Lancaster grew, they became more sophisticated and structured yet some of the links between organizations then weakened and so they became less comprehensive. There were four key elements identified as to why professionalization of these services occurred. First, there were professional, political and economic mechanisms in the wider milieu impacting on the shape of services. For example, earlier I reported how Elspeth Hopkins became a volunteer Breast Cancer Support Nurse and started support services. In the course of time this became a funded position but not until 1992, 10 years later:

“...things were changing nationally...It was becoming very obvious that you had to have a breast care nurse in post because you had to meet all the criteria that was in the breast-screening unit...they got money...to make me full-time” (Hopkins, 2010)¹⁰⁹.

A full-time nurse was needed in order to meet criteria and secure a breast screening service in the community. By now there was an overarching plan that recognized the importance of having a Breast Support Nurse within the National Health Service. The strategy imposed formal requirements for breast screening and cancer services generally, which in turn brought change that was for the better because it enabled the nurse to provide a full time service (Department of Health, 1995; Department of Health 2000; National Health Service Breast Screening Programme, 1992) (see chapter 1). Now the flexibility of the breast cancer support service disappeared as consensus emanated from the strategy to stipulate what kind of service was acceptable (like the stabilization of technology - Pinch and Bijker, 1984).

Second, in time the cancer support services became much busier and this brought more therapists, policies, rules, health and safety requirements and managers (Howarth, 2010)¹¹⁰.

By this stage CancerCare had grown to such a size and complexity that a full time administrator was required to manage it and David Hopkins was appointed (Hopkins, 2010)¹¹¹. Cancer support services became more organized, Peter Hearne initially a hospice volunteer and later General Manager at CancerCare explained that this increased the administrative workload (Hearn, 2010)¹¹². Yet in the early days when the services were small there was far less administration, and the small size of the facilities made it possible to provide care that was tailored to meet individual needs. By way of illustration, when nurse Chris McCann started in 1994 she initially only saw individuals with cancer, over a 10-year period although services grew the numbers needing care were still manageable and not too large to be ‘unwieldy’ (McCann, 2010)¹¹³. Later on Macmillan nurses stopped attending the drop-ins, which had been an integral part of the Cancer Support Nurses role because they extended services to all those with palliative needs. There were both beneficial and negative consequences of this change as services included a wider group but nurses were no longer available to provide support at the drop-ins (McCaldin, 2010)¹¹⁴. The ‘Cancer Support Nurse’ evolved into ‘Macmillan Nurse’ and then ‘Palliative Care Nurse’ as services expanded:

“...it did become too big...to manage...A palliative care nurse was appointed...it had grown so much, and changed quite significantly...became so bureaucratic...I’d have to fill in a form...which would then be taken by the admissions meeting the following day...We were just a small cog in a big organization by this point...people weren’t listening to us...” (McCann, 2010)¹¹⁵.

It was clearly advantageous for more people to access these services, yet some of the personalized supportive care provided by Cancer Support Nurses in the early days could not continue. The relevance of this to the development of *tripartite* services was that the connections with the drop-ins were broken. Growth was not simply about seeing more people with cancer; it was also about including all those with palliative care needs.

Third, by now Macmillan nurses saw fewer individuals with cancer because Cancer Specialist Nurses evolved and divided people up according to the area of the body affected by cancer. This suggests that there had been a shift towards holistic practice initially, then over time more people used the services and they became so specialized that some conventional practices began to re-emerge. It appeared similar to concerns that palliative medicine was becoming focused on ‘symptoms’ (Kearney, 1992). For example, care

became task driven according to which ‘part’ of the body had been diagnosed with a ‘specific’ form of cancer. Fourth, regulations increased which made services more ‘professional’ but then there was a fettering of autonomy:

“...we were very lucky that we lived in a time where people with creative ideas could follow those through...I’m not very keen on rules and regulation. I suppose I trust people...too many regulations undermines trust...” (McIllmurray, 2010)¹¹⁶.

Some participants did not see the increased bureaucracy, rules and structured practices as advantageous. In the early days when the cancer support services had been relatively compact everyone knew each other, and there was a sense of camaraderie which encouraged creativity. Having confidence in colleagues and being able to rely on them were particularly notable qualities in a small organisation. By contrast, bureaucracy created suspicion because it undermined trust, and one of the disadvantages of professionalization was the service lost the feeling that everyone was involved in the same way (Johnson, 2010)¹¹⁷. For example, in the early days individuals volunteered but the atmosphere changed when people were paid:

“...the change...people...doing it for nothing...for the goodwill and the feeling it gave to being taken over as a business and run by professionals...you lost that feeling of I am doing something because I want to do it...not...because I’m paid...” (Youren, 2010)¹¹⁸.

We can see here that during the metamorphosis from an intimate service to a structured business the goodwill that came from a vocation was lost. Similarly, the level of formality changed attitudes and therapists did not give as much of their time freely:

“We had some absolutely marvellous therapists...really dedicated, inspired...I’m not saying that therapists...are any the less dedicated but...one of the thing about professionalization is that it has changed people’s attitude...in the early days...you would have never heard any therapist talk about time off in lieu...” (McCaldin, 2010)¹¹⁹.

Professionalization was changing the work ethic and this brought negative consequences as therapists did not work as many hours. Consequently, the cancer support services became increasingly more structured:

“...Once we formalized the assessment that came, partly at the request of the Macmillan nurses they felt the way they were trained had to be more formalized entry approach...and also because of the money. That...created a different atmosphere...formalization...professionalization...has made things much harder...certainly in this kind of organization...it really is a constraint...” (McCaldin, 2010)¹²⁰.

The flexibility of the early service when Cancer Support Nurses decided whether a person needed complementary therapy disappeared as pressures introduced ‘structured assessments’ to determine whether individuals required this facility. Later in time nurses needed more structured approaches because of the way they had been trained. The therapists by comparison had operated in a similar flexible way to the Cancer Support Nurses, but as services became more formalized this made creative practice more difficult. Yet standardization resulted in therapy that was of a similar standard, albeit not as personal. At the very least these changes brought a level of governance and that was a positive feature because it meant “...tighter requirements and a lot more reporting back...” as Gill Ormerod one of the first counsellors recalled (Ormerod, 2010)¹²¹. In the light of the expansion CancerCare remained outside the National Health Service because it was thought that this would reduce external influences:

“If we came under the NHS which we inevitably would...if we...were financially linked...we would lose a lot of our independence and our ability to work with the kind of integrity we've tried to always bring into the work that we do...It's this direction from the top all the time” (McCaldin, 2010)¹²².

There were concerns over differences between local philosophy and national strategy and how this might shape cancer support services. Similar concerns have been documented in other places where tensions have occurred between local autonomy and nationally led, top-down priority and standard setting (Small, 2003). Accordingly, it was considered necessary for the cancer support service to remain independent in order to retain some of its flexibility in the provision of psychological, social and spiritual care. The ethos contrasted

with conventional approaches that privileged physical problems over emotional needs. Those practising in the field were in the weaker group, and if they had merged the burden would have been on them to show that supportive care was credible (McIllmurray and Holdcroft, 1993). Nicolson and McLaughlin (1988) found similar challenges amongst different groups in the debate over the aetiology of multiple sclerosis (see chapters 1 and 2). Similarly, Small (2000) also found that one of the reasons for hospices staying outside the National Health Service appeared to relate to personal appeal for independence, which some did not think they could find elsewhere (see chapter 1). Nonetheless, whilst the services in Lancaster remained independent there were social and economic forces at work that increasingly shaped them, as they expanded and became more professional.

All of these illustrations inform us that expansion and wider social, political and professional factors impacted to limit interpretative flexibility (when services were open to more than one approach), as consensus emerged to confirm that a more structured service was acceptable and standards were put into place. This was similar to the second and third stages of technological developments (Pinch and Bijker, 1984) (see chapter 2). Yet the change weakened links between services so that they were not as comprehensive (James and Field, 1992) (see chapter 6). The next section analyses similar changes that were also taking place at the hospice.

4.7 Professionalization of the hospice

Similar patterns of structural change were at work within St John's Hospice. There were seven key changes detected as to why the hospice services developed in a more professional way. First, in 1993 questions were raised about whether the social day care, which had helped the hospice to broaden its impact should evolve into a more conventional medical day care facility. The Trustees asked local General Practitioners whether they believed the community needed a 'hospice' rather than 'social' day unit¹²³. The involvement of local doctors was likely to have been a significant factor in the success of the project because they were involved in making decisions about the service. Similarly, the 'hospice at home service' started by palliative care consultant Mary Baines and nurse Barbara McNulty at St Christopher's Hospice also involved General Practitioners. Mary Baines found that it was important to ascertain what general practitioners wanted because they had been in charge of patients in the community, it was then possible to work with them and reduce tension (Overy and Tansey, 2012) (see chapter 1). The overwhelming

response in Lancaster was that medical day care was needed, therefore the service evolved and Susie Bulman was appointed Sister. Subsequently, the services became more professional and individuals were able to move between social day care, which then took place at Slynedales and medical day care which was available at the hospice. It became possible to provide 'hands on' personal care, for example baths and some treatments such as dressings at the hospice day care facility¹²⁴.

Second, in 1994 Sister Aine Cox retired from the hospice and Susie Roth took over as Matron, it signified an era of change as for the first time Matron was a nurse rather than a religious sister. Consequently, Susie Roth saw herself as 'the link between the old and the new' during a period of intense professionalization where there was a greater need to adhere to regulations to drive up standards and survive annual scrutiny from the Inspectorate (Roth, 2010)¹²⁵.

Third, the hospice had to comply with other requirements in the broader context so that it could be registered to take a child for respite care. In the past the Nuns 'could get away with' more informal approaches than the nurses could, and the hospice had to be brought in line with national standards and health and safety requirements (Roth, 2010)¹²⁶ (see chapter 6). Around this time Susie Bulman became deputy Matron as well as Sister of day care. She indicated how professionalization fitted with the hospice changing from a place that provided palliative care to one that gave specialist palliative care:

“...she then took the hospice from being a quality nursing home with very good intentions into becoming a proper hospice...Margaret Ellam was appointed as a full-time specialist consultant and Margaret then with Susie took it on to become specialist palliative care unit...with...policies in place...for training, more formal...more recognition of standards” (Bulman, 2010)¹²⁷.

Broader professional mechanisms impacted on developments which changed the hospice into a specialist palliative medical unit. Its function initially had been to provide support, respite and terminal care to those with cancer or other chronic illness. Fourth, the appointment of Margaret Ellam as an Honorary Consultant in 1996 was an important turning point in the development of local specialist palliative care. It was necessary to get a specialist team in the hospice in order to be recognized as a specialist unit, and it was

typical of change taking place nationwide (Ellam, 2010¹²⁸; James and Field, 1992). Furthermore this recognition occurred in the context of a more widespread shift towards medical specialism generally (Small, 2003). Yet in the early days funding was inadequate and the hospice had ‘run on a shoe string’ with poor levels of staffing. Services could only operate because the pioneers were prepared to put in so much extra work to ‘plug the gaps’ and this was also a widespread situation around the country (Ward, 2010)¹²⁹. Fifth, as there had been this heavy reliance on goodwill in the past, individuals often worked very long hours in their own time but this was unsustainable by the mid 1990s because there were greater expectations:

“...straddling the vocation with the realization that young, newly qualified nurses, are not going to accept no pension scheme or working for a year without paid holiday...” (Roth, 2010)¹³⁰.

There was a demand for greater structure to the way individuals worked; employees’ rights improved and the nurse’s role changed from being a vocation to one which was more structured with greater opportunity for promotion and salary increases. This progress meant it became easier to retain newly qualified staff because the terms were more appealing to those qualifying in a modern period (see chapter 6). The structure of the hospice became more complex and a General Manager was appointed, yet in the past the Matron had doubled up as the manager. The hospice conditions were not as ‘spontaneous’ as they had been but now individuals were treated in a similar way, and people knew what to expect:

“...people aren’t treated as...arbitrarily...as they were...it’s more conventional...so in becoming like that, it’s lost a bit of it’s...delightful spontaneity, when the...Nuns were all in charge and anything could happen...But...anything could happen in a bit of an awful way...too...if things happened that weren’t fair...It’s more...structured really, but in some ways it’s none the worse for that” (Corkill, 2010)¹³¹.

It seemed that the creative impromptu care was beneficial if all went well and suited the individuals concerned, but it was not acceptable if things did not go to plan. In those circumstances regulations were welcomed because they made circumstances more equitable. Sixth, throughout the evolution of the hospice the specialist team continued to

develop. Leah Dalby started physiotherapy in 1995, this was soon followed by occupational therapy (Dalby, 2010)¹³². In 1996 the multidisciplinary team expanded to include Maureen Goad a Social Worker, yet there had been some tension over this:

“...eventually, they did...appoint me, but only after I had to give a presentation to the trustees about why they needed a social worker ‘cos they still couldn’t see any purpose for one...it was the first social work post...I had to set up the system from scratch...” (Goad, 2010)¹³³.

The example shows the coming together of the multidisciplinary team, it also suggests that those in the field held different perspectives on social work and these changed with time. For example, some could not see its value, yet others appreciated the contribution it could make and this was reflected in the decision to appoint a hospice social worker. Soon a structured bereavement service developed that involved long term contact with the family, thus expanding the multidisciplinary care. Clark et al (2005) also found that multidisciplinary teamwork and the ability to work together in a variety of ways for a common purpose was important, despite tension and conflict. By 1996 the medical, nursing and paramedical staffing had expanded to the extent that it was finally considered ‘adequate’¹³⁴. Seventh, around this time admission criteria were introduced because there was a need to focus services on those with specialist palliative care needs. Consequently everyone had to be more careful about who was admitted because they had to justify the need (Dalby, 2010)¹³⁵. For some, these developments were not an improvement:

“We had two patients with multiple sclerosis they...had been told they couldn’t come after 12 weeks...I find that very disturbing...they wanted to come but they were told, no” (Carne, 2010)¹³⁶.

The focus was now on specialist palliative care, therefore those who could no longer satisfy the admission criteria could not access services. The change also rationed what was available to those who fulfilled the requirements. Yet in the beginning people attended day care for as long as they wanted because no one was ever discharged. Generally the introduction of protocols brought a concomitant loss of flexibility in the way individuals worked:

“...so many things are done according to protocol...once you start trying to define the situations...you lose a lot of the flexibility that we enjoyed...what you’d find is that there are...very definite criteria about who we will accept and who we won’t...if I were to phone up...and say...I’ve got a patient who’s...combination of drugs...who’s really struggling...4 or 5 days their problems will have resolved but they really just need a bit of loving care and pampering...they would say I’m sorry but you’ve come to the wrong place that’s not how it works now” (McIllmurray, 2010)¹³⁷.

This suggests that palliative care protocols were tantamount to the emergence of consensus and limitation of interpretative flexibility described by Pinch and Bijker (1984) because they determined who could access the service. The additional structure facilitated admission for individuals that needed specialist palliative care but excluded those that did not. The hospice needed to gain accreditation as a specialist palliative care unit as I have explained ¹³⁸, however in developing necessary protocols palliative care ‘lost some of its quirkiness and homely feeling’ (McCann, 2001, p.14). There were other challenging consequences, for example beds were sometimes empty because the criteria for admission could not be fulfilled:

“I found it difficult...when people had to move on after the Nuns had gone...to nursing homes if...they might have had a longer time to live...they had to have a better turnover in beds...looked at it in a much more business like way...relatives would...say... ‘you could come in and you stayed, so I’ve given up a flat, I’ve got rid of the furniture (laughs) because I thought she’d be staying.’...I’d say ‘that doesn’t happen now.’ It does seem very hard to say, but it was more or less, ‘she’s going to be too slow dying, so you can’t really take up the bed indefinitely’...there were times then when them beds were empty because you had criteria to fulfil for people to come into those beds...” (Goad, 2010)¹³⁹.

When the focus was on specialist palliative medicine perspectives became linear and the rational criteria prevented using the beds for those with wider problems (Chagas, 2012). The approach contrasted with earlier practices because in the beginning the aim was to fill the beds, and the hospice was seen by some as a place to go and stay until death occurred whenever that might be (Corkill, 2010)¹⁴⁰. Accordingly, it was this flexibility that collided with specialist palliative care because that was based upon a style of inpatient care which

was “...in and out rather than coming in and staying for weeks on end” (Ellam, 2010)¹⁴¹. Similarly, in ‘*A Bit of Heaven For The Few*’ Julia Franklin, Social Worker recognized that there would be tension between keeping to the original hospice philosophy and actually becoming acute specialist palliative care units, it was important to have leaders that could manage these challenges (Clark et al., 2005).

Moreover, the adaptable relationship that had existed between the hospice and cancer support services in the early days also changed. For example, in 1998 the idea of merging CancerCare and the hospice was debated, but it was decided not to take this route because there was concern over increasing medical influences on hospices generally. CancerCare was more flexible because it was not too tightly tied to medical protocols¹⁴². Over time relationships between services also became more structured. If an individual at the hospice wanted to use complementary therapy the therapist from CancerCare had to be ‘employed’ on a contractual basis. Consequently the links between the organizations weakened, as the hospice became more independent and developed its own therapies (Warren, 2010)¹⁴³. The relationship between this and the development of the *tripartite* services was that the connections were no longer as strong and the services were not as comprehensive.

4.8 Summary

This chapter shows that in the absence of a national plan local grassroots activists created *tripartite* cancer and palliative care services from scratch, out of few tangible assets yet with enormous drive and hard work. The cancer support and palliative care services in Lancaster developed outside the mainstream health service provision but alongside oncology services, and this made them comprehensive. The great strength of oral history was that it uncovered differing accounts about developing these services and enabled me to interpret the meaning participants attached to experiences. I was able to make links between accounts and individual and social factors that acted as catalysts in the change. In addition this revealed connections between oral history accounts and the social, historical, professional, political and economic mechanisms in the wider context that impacted to shape facilities (Mallinson et al., 2003; Thompson, 1988). For example, social and economic structures shaped the development of these services because the Nuns were available to staff the new hospice. The Health Authority was able to transfer the contractual arrangements that it had with St John of God to St John’s Hospice, which

secured the workforce and finances to meet the running costs of the hospice. Also, there was much overlap between the cancer support services and the hospice; the key reason for this was because many of the individuals were involved in all the organizations and were also connected to one another socially and professionally. These characteristics had the effect of bringing those involved (and therefore the organizations) together, so that they then operated more cohesively than they might otherwise have done.

Similarly, CancerCare shared the hospice premises for a number of years, and this arrangement broke down some barriers and encouraged individuals to use the cancer support services at the hospice. The flexible relations between these services resulted in individuals accessing the hospice at early stages of their illness, as well as at the end of life. Moreover, these social and economic factors impacted to provide hospice services that were not exclusively for people with cancer but included individuals with long-term medical conditions. In addition, those with multiple sclerosis also used the hospice for respite care because of social and economic links with the Multiple Sclerosis Society. There were also connections in the broader arena when the Association of Cancer Physicians became interested in the development of services in Lancaster, and they wanted to explore the future developments of district cancer services at national level (Association of Cancer Physicians, 1994; McIllmurray, 1987). Over time, wider professional factors also impacted to shape the local services (Association of Cancer Physicians, 1994; Department of Health, 1995; Report of the Working Group on Terminal Care, 1980).

In the beginning interpretation of the macro level of the local climate uncovered how flexible services were, in a similar way to the first stage of the EPOR in the development of scientific knowledge (Pinch and Bijker, 1984). Consequently the cancer and palliative care services had different meanings for the actors and approaches were also flexible. As a general point this flexibility allowed services to shift away from conventional hierarchical practices to an approach where facilities were provided by a multidisciplinary team, and patients became involved in decisions. It also changed the focus of care to encompass emotional as well as physical needs. Pinch and Bijker (1994) found that in the second stage of the EPOR flexibility disappears, as consensus emerges to say what kind of service is acceptable. The third stage links closure mechanisms to the wider social-cultural milieu. In this case practice and policy began to be shaped by the external social, political and professional forces described. These stages became less malleable over time and gave way to professionalization of the cancer and palliative care services as the hospice became a

specialist palliative care unit. Standardization and routinization brought respectability and secured accreditation as a specialist unit (James and Field, 1992). Yet standardized measures suppressed creativity and flexibility. McGrath et al (2005) found in Australian palliative care that increased bureaucratic pressure to measure and quantify undermined holistic care. I have explained that such tension, between local autonomy and top-down standard setting has been recognized as a challenge to the development of palliative care (Small, 2003). The local cancer and palliative care service developments in Lancaster were ‘time’ specific. They might also have been ‘place’ specific. I have identified that there is a gap in our knowledge about how local services evolved, and further research is needed to confirm what happened elsewhere. This chapter goes some way to answering the research questions about family/life experiences and their impact on developments. It also addresses questions about how individuals became involved in cancer/palliative care, their philosophy, how it felt to be involved, the therapy/support provided, bonds formed, charisma, routinization, research/education and change. It has begun to address three of the aims of the study – ‘to ascertain how individuals developed cancer and palliative care services in one community’, ‘to place the research findings about service development in the wider context of cancer and palliative care issues’ and ‘to increase understandings about the development of cancer and end of life provision over time’. I will now proceed with chapter 5 which explores the themes philosophy of care and practice.

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² Parker, L. (no date). A History of St John’s Hospice, Lancaster 1976 to 1986.

³ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellet on 25 May.

⁴ McIlmurray, G. (2010). Interview with Sara Denver in Over Kellet on 11 October.

⁵ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellet on 25 May.

⁶ Holdcroft, P. (no date). The Development of District Services for Cancer Patients and their Families in North Lancashire and South Lakeland from 1978.

⁷ Youren, P. (no date). The Development of District Services for Cancer Patients and their Families in North Lancashire and South Lakeland from 1978.

⁸ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellet on 25 May.

⁹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

¹⁰ McCann, C. (2010). Interview with Sara Denver in Grange Over Sands on 5 October.

¹¹ McIlmurray, G. (2010). Interview with Sara Denver in Over Kellet on 11 October.

¹² Holdcroft, P. (1990). Pippa’s Philosophy for Slynedales.

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¹⁸ McIlmurray, M. (no date). Cancer Treatment Services in Lancaster and South Cumbria Health Districts.

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- ²⁵ McCaldin, M. (2010). Interview with Sara Denver in Stocksfield 9 October.
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CHAPTER 5

PHILOSOPHY OF CARE AND PRACTICE

5.1 Introduction

The purpose of this chapter is to explore the philosophy of care and practice behind the *tripartite* services that evolved in Lancaster. It describes the history that led to their development in order to gain a deeper understanding of the ethos. It demonstrates that the methodology underpinning the study complemented the method because accounts resonated with elements of social constructionism. For example, there was evidence that participants questioned conventional philosophy and looked for different ways to provide care. This chapter also explores the meaning of compassion and how the participants provided compassionate care. It will address the second aim of the study – ‘to capture experiences of how care was provided at the end of life’. It also adds to the knowledge that emerged from chapter 4 and takes matters a step closer to addressing the other aims of my study, and the overarching research question - ‘How were cancer and palliative care services developed in Lancaster 1976-2000?’

5.2 Historical encounters

Several participants revealed there was very little to draw on from their training that was of any help when they developed palliative care. Besides, patients needing palliative care were generally seen as medical failures and there was little interest in the field (Demoratz, 2005; Saunders, 2000; Seymour et al., 2004). When participants began to forge new paths in Lancaster they drew on previous life events, or on experiences in non-specialist settings. Four key historical factors provided some background context which increased understandings of the philosophy underpinning the cancer and palliative care services: life experiences, understanding the family, early professional encounters and lack of emotional training and these are now explored in detail.

5.2.1 Life experiences

Some individuals were able to draw on previous encounters in life to help them when they began to provide cancer and palliative care:

“...it’s not that I believe you have to have actually done something to understand it, but it doesn’t half increase your empathy, if you have had some personal experience...I have had a lot of life experience and I have...had a disabled child who died at 9 months old...there are other very close deaths in my life” (Youren, 2010)¹.

Here we see how the richness of life shaped practice; the account suggests that positive experiences as well as traumatic events were valuable because they increased the ability to be empathetic. Similarly, experiencing the death of a loved one could be drawn on at a later time to help individuals care for those with cancer and terminal illness:

“...My mother died when I was eight...” (Carne, 2010)².

If the loss of someone close could have impacted on participants becoming involved in this area of work the connection was not necessarily apparent to them at the time. Yet it was a recurring feature:

“...nearly all of us involved in the work...Malcolm’s own mother, she died of cancer...my good friend Lizzie...it gives you a window onto things...a better understanding of how people are feeling...to see what is happening to this person, is actually meaning for them” (Youren, 2010)³.

This intimates that the experience of loss enabled participants to ‘see through someone else’s eyes’ and be more empathetic. Furthermore, the philosophy was also about learning from the patient what it was like to live with illness. In these approaches there were two connections identified between the oral history accounts and social constructionism. First, the participants’ questioned the rationality of practices that assumed professionals knew best and second, they searched for other ways to provide care (Pinch and Bijker, 1984; Walmsley and Atkinson, 2000) (see chapter 2). By listening to those with cancer it was possible to identify that they had different needs. It also became apparent that involvement of the family was important and this issue is explored next.

5.2.2 Understanding the family

It was important to care for the person in the context of their life and therefore it was common practice for family members to be included in cancer care. In chapter 4 I explained that a Relatives Support Group was created and the family were often involved in practical activities such as cooking (Youren, 2010)⁴. This might have made them feel like they were doing something useful, and it also provided some control of a situation that was otherwise out of their command. Accordingly, cooking could be done by everyone not just people with cancer, so it possibly provided some comforting ‘normality’ to an otherwise disrupted life. Moreover, these social mechanisms brought families together to support each other. Similarly hospice day care was another important resource for the family because it gave them a break, even if only for a day (Shepherd, 2010)⁵.

5.2.3 Early encounters

Here we get an insight into how care was provided at an earlier time in other places, and the impact of historical experiences on the development of local cancer and palliative care services in Lancaster. Many participants had trained in different areas in the country and had seen examples where it was conventional to isolate those nearing the end of life:

“...a little boy who was only about five...had bowel cancer...people just pulled the screens down each side...most of the cancer patients...didn’t have specialized care...they...were just screened off...and left to their own devices...” (Shepherd, 2010)⁶.

“...looking after a...dying patient...just drawing the curtains round them with a little gap so you saw them every time you went up and down...I would not ever say we sat for more than a few minutes...” (Warren, 2010)⁷

Individuals nearing the end of life were avoided because those caring for them did not know what to do/say; they had no training in terminal care and tried to conceal it by drawing the curtains around the bed. Maguire (1985) argues that this kind of approach was taken so that those involved could avoid confronting awkward questions such as ‘Is it cancer?’ or ‘Am I going to get better?’ or ‘How long have I got?’ (Maguire, 1985, p.1712). Fordham and Dowrick (1999) found that the shortcomings were because clinicians ‘...saw

their main functions as diagnosis and attempts at cure' (Fordham and Dowrick, 1999, p.574) rather than caring for the dying (see overlap with chapter 4). Mills, Davies and Macrae (1994) studied dying patients in four hospitals and revealed that although more than half retained consciousness until shortly before death, doctors and nurses continued to avoid those entering the last stage of their life. All of these illustrations suggest that terminally ill persons were isolated and this increased as they neared the end of life. One key reason for this pointed to the lack of training in care of the dying.

5.2.4 Lack of emotional training

There was evidence that a paucity of emotional care training left participants 'ill prepared' to provide cancer and palliative care:

“...one of my very first experiences...was if somebody was dying...I realized that I had nothing in my armamentarium to handle that...we had no training in...end of life” (Warren, 2010)⁸.

Medical training in the 1960s centred on the mechanical aspects of illness, as a consequence there was little psychosocial teaching. Instead the focus was on anatomy, physiology, biochemistry and the 'physical examination' (Ellam, 2010⁹; Williams, 2010¹⁰). Within this environment the attention was on 'curing' illness rather than on palliative care, and when a patient was 'incurable' surgeons often delegated the care to nurses:

“...he would chop a leg off and...put it in the hands of the nurses...not palliative care treatment...” (Lomax, R. 2010)¹¹.

Palliative care was not seen as important therefore surgeons willingly referred the emotional care to nurses, who were mainly women in less influential positions. Payne (2010) argues that roles which involve a caring element have often been viewed generally as women's work and afforded less prestige. Similarly, oncology training also concentrated on aggressive treatment rather than palliative care:

“I didn't learn palliative care skills...it was...sophisticated...nobody died there...it was very aggressive...the emphasis was on living at whatever cost...” (Hunt, 2010)¹².

Oncology training focused on ‘cures’ whatever the cost rather than learning how to provide holistic palliative care and as explained - professionals often kept at a distance from those nearing the end of their lives. Maguire (1985) found that doctors and nurses used the distancing tactics to avoid getting close to emotional suffering and to protect themselves. Conventional approaches discouraged individuals from talking about concerns and these acted as barriers to effective psychological care. Nevertheless, throughout the 1970s a culture of silence persisted as Margaret Ellam, hospice palliative care consultant explained when she reflected back on an earlier experience from elsewhere:

“...a young man... dying of lymphoma... We all sidelined him...this chap after some weeks would look to be asleep...we’d say oh good and go around his bed...and I realised that he was not asleep at all...probably was just protecting himself...I certainly completely mismanaged him...I did not go and just chit-chat about anything. I avoided him” (Ellam, 2010)¹³.

When it was thought that ‘nothing could be done medically’ there was also a feeling that nothing could be done at all (Fordham and Dowrick, 1999). Yet in the course of time there was a realization that emotional support was important, as Mike Warren General Practitioner indicated:

“...we went to see this man...he had lung cancer and was clearly not going to live very long...but nobody...had talked to him about it...his wife said... What should she say...I said, ‘Surely, we must talk to him...find out where he is so he can do the things that people sometimes want to do’...the next door neighbour who’d been a...matron, a classic...said, ‘People with cancer should never be told’...she ruled the roost...But it...struck me as very inappropriate...he died within the next day or so...nobody had ever taught us so that was...a seminal moment...his wife...she had no opportunity...to say goodbye... I didn’t know what to do but my instinct was that you go and talk to him...” (Warren, 2010)¹⁴.

Despite the culture of silence some individuals recognized the need for honesty but others did not share that view and wanted to maintain secrecy (Demoratz, 2005). In addition, the reflection signified the need for change because it was the catalyst that led Mike Warren into hospice and palliative care work (see chapter 4). The oral account questioned the rationality of secrecy in respect of diagnosis and prognosis. Furthermore, it suggests there

were relativistic practices because there was a desire to look for alternative ways to care for the dying, and this was similar to symmetry described by Pinch and Bijker (1984) in the development of scientific knowledge. Despite the lack of guidance other individuals also identified that there was an urgent need for holistic/emotional training:

“...we started a sort of adjunct to the clinic which was normally about measuring urea levels and filling jugs...and left a whopping mountain of distress, which we were left unable to deal with...beyond just...kindness...” (Ormerod, 2010)¹⁵.

Despite a desire to help emotionally there was a lack of knowledge as to how to go about this because people were not trained. Nevertheless, some participants were able to draw on earlier training to help them later with hospice work:

“I went to St Thomas’ in ‘67...You put the patient first...I suppose it influenced where I am...much more in the kind of psychological aspect of how patients...might want things” (Bulman, 2010)¹⁶.

This sheds light on the importance of education because it was possible to teach professionals to ‘put the patient first’. Furthermore, psychological problems were acknowledged, there was a desire to ‘see’ things from the other person’s perspective and plan care to meet their needs. St Thomas’ was of course where Cicely Saunders had trained as a nurse and doctor, and this kind of philosophy was reflected in her own practice (Saunders, 1996). The evidence in this chapter so far has painted a picture of what it was like in other places before local cancer and palliative care services began. It has revealed that generally there was a lack of guidance on palliative care during medical and nurse training. Yet participants were beginning to challenge convention and search for new approaches to the provision of care. I will now explore their philosophy of care.

5.3 Philosophy

This section explores the philosophy underpinning the local cancer and palliative care services when they began to develop in Lancaster. It starts with some general observations on philosophy and then it examines the constituents of compassionate care in order to show that the proponent’s approaches were compassionate.

5.3.1 General observations of philosophy of care and practice

My overall interpretation was that philosophy meant different things to different people, these were some of the constituents: a positive attitude, a caring approach, facilitating autonomy, listening, using supportive therapies, wanting to smooth things over and collaboration. I will explain each element in turn.

Positive attitude

In the early 1980s the ethos behind the cancer support services was about living 'positively' with cancer, yet it was a difficult message to portray because "...people were still at the stage of thinking it was contagious" (McCaldin, 2010)¹⁷. There were huge hurdles to overcome and proponents tried to promote the idea that 'you can live everyday' or you can 'treat each day as if you are dying' (Youren, 2010)¹⁸. Similarly, it was important to 'live for the moment in spite of serious illness' (Roth, 2010)¹⁹. There was a sense of the seriousness of the situation because in many cases chemotherapy was for palliation. In these circumstances Millie Shepherd explained to individuals that chemotherapy was not curative but it might help increase life a little, or make it more comfortable (Shepherd, 2010)²⁰. On a critical note, the positive approach benefited some but there might have been others who were less comfortable with it because they did not want, or were unable to 'see' cancer in an optimistic light.

Caring approach

The philosophy encouraged a caring, familiar environment where people could get in touch with the same Cancer Support Nurse. The consensus advocated flexibility within the service and individuals were told "... 'you can ring me anytime' ..." (Youren, 2010)²¹.

Furthermore the philosophy encompassed holistic care:

"...every aspect...was important...not just their physical wellbeing but...mental wellbeing...if they had families. The total person was taken care of..." (Shepherd, 2010)²².

The cancer and palliative care services in Lancaster were underpinned by a philosophy that tried to provide care to meet emotional as well as physical needs. Patients had considerable

emotional problems and these were beginning to be taken seriously (McIllmurray, Gorst and Holdcroft, 1986; Soothill and Thomas, 1998) (see later discussion on compassionate care). The philosophy of care at the hospice was also described as kind and warm, although at times there could have been a greater capacity for understanding and sharing another's feelings:

“...it was very loving...the Nuns had...the intention of great kindness and inclusiveness...Aine in particular...there could have been a...deeper degree of empathy for patients and relatives, a deeper understanding of...their fear of coming into hospice...But...so many...felt there was time...warmth and a loving kindness that they didn't always experience in the NHS” (Bulman, 2010)²³.

There was a ‘stigma’ associated with the hospice; many had a ‘real’ fear of going into a place where they believed they might never leave because they would end up dying there.

Increased autonomy

A key aim of the cancer services was to increase autonomy and one way of achieving this was to let individuals ‘self refer’ if they were concerned about themselves (Youren, 2007). The approach was very unusual because in most other areas of medicine the convention was to accept ‘doctor to doctor’ referrals only. Furthermore, there was a need to ensure people were given honest information so that they could make informed decisions, and this also challenged the routine practice of not telling a person about their condition (Warren, 2010)²⁴. It was a radical approach because at the time the word ‘cancer’ was not even discussed, and some doctors used all kinds of euphemisms without using the word cancer (Youren, 2010)²⁵. There was a need to open up the whole debate on cancer care and educate people that cancer was not contagious. Many found that when they had been diagnosed close friends or relatives treated them like ‘lepers’ and would cross the road rather than talk to them because they did not know what to say. There was also a perception that once a cancer diagnosis was made a person was dying, so there was a need for more information to increase awareness that early treatment could give people quite a lengthy period of life (McCaldin, 2010)²⁶. These examples indicate that there was a lot of misconception in relation to cancer, therefore cancer support aimed to provide information so that individuals could make decisions about their care (Clark et al., 2005; Tattersall and Thomas, 1999).

Listening

Many participants reflected on the importance of listening in an attempt to identify what problems people faced in the context of their culture. For example, sometimes there was a denial that the end of life was nearing:

“...woman with advanced breast cancer...Optimistic in the early days but you could see that diminishing as symptoms...progressed...she rang me...‘I wonder if you could come and talk to my husband.’...‘He’s having a great deal of difficulty accepting it...he won’t talk to me...I know I’m dying, I need to talk to him about...my funeral...my daughters...’ he said, ‘I don’t want any negative talk’ I just said, ‘What do you want to hear?’...he said, ‘I want you to tell me how well she’s doing.’...bit by bit challenged all the unrealistic issues...tried to make him see from her point of view, that...she wanted to talk...about what was happening...he was her soul mate...everything that she could have ever wished for in a husband and father, but he wasn’t allowing her to talk...about these most important issues...And he just howled. He rocked, and he sobbed, and...he raged against it...I went to put my arm on...his shoulder, and he just put his arms round me...he just sobbed, and sobbed and sobbed. ‘I can’t do this, I can’t live through this...I’ve just got to walk out that door and never come back.’ We just had to talk through all of this...eventually, he felt...he was ready to face her...she walked in...sat down, and he just went to her and knelt on the floor, put his arms round her and sobbed into her lap...she just stroked his head, and it was the most moving thing I’ve ever witnessed...I didn’t say a word...I just sat there, and sobbed with them...”
(McCann, 2010)²⁷.

The ability to listen was essential because it enabled participants to detect what was needed when there was tension between denial and the need for honesty in the face of death (Bowman and Singer, 2001). Saunders (1996) also found there was tremendous value in being able to listen in the context of a person’s culture because needs were expressed differently. It was necessary to try to enable the relative to ‘see’ phenomena from the dying person’s perspective, rather than ‘seeing’ their own viewpoint as being ‘correct’, which was similar to the doctrine of symmetry in the development of scientific knowledge (Pinch and Bijker, 1984). It was then possible to provide the support the person nearing the end of their life needed, and this was a key quality of compassionate care (see later in the

chapter). Nevertheless, in some circumstances the pressure had to reach crisis point before a transition could start to take place from denial to managing a situation. Notwithstanding that it was clearly a very difficult process and one that had to be left until the final stage in some cases.

Using supportive therapy

The philosophy of those providing cancer support services valued complementary therapy, and proponents tentatively suggested when individuals might find it helpful (see chapter 4). Nevertheless, it was important to explain that this would not necessarily help the ‘disease’ but might make one ‘feel’ better, it was not offering cure but instead ‘ways of getting through’ the circumstances in which people found themselves (Youren, 2010)²⁸. Furthermore, the provision of therapy provided an opportunity for individuals to meet others who were going through similar experiences. Instead of feeling alone they came to understand that they were ‘in the same boat’, which helped reduce anxiety (McIllmurray, 2010²⁹; Youren, 2010³⁰). Moreover, the philosophy challenged the rationality of disease-orientated treatment and gradually introduced change whereby emotional problems were ‘seen’ to be as ‘real’ as physical ones (McIllmurray, Gorst and Holdcroft, 1986; Soothill and Thomas, 1998).

Wanting to ‘smooth things over’

The interview accounts revealed that there were differing philosophies of care and these were not always complementary:

“There was always a dimension...of wanting to make everything alright...not to face the terror of it...a lot of the volunteers struggled...They wanted their role to be...a good worthy experience of making things alright...happy...cheerful and cosy. That was something I found difficult...it wasn’t the truth...I wanted it to be real...to allow the culture to be containing and safe...but...not to go down the path of a denial...one has to work with that because...people...have their own understanding of death...” (Bulman, 2010)³¹.

Tension arose at times over different philosophies, and one reason for this was because many people were involved in providing care so they brought a range of perspectives.

These varying multidisciplinary viewpoints played a part in shaping consensus, which confirmed that a very flexible kind of service was acceptable initially. Nevertheless such flexible practices could prove difficult at times, for example when some volunteers wanted to ‘smooth things over’ and ‘make everything alright’. Other accounts suggest participants wanted individuals to talk about how they felt so that they could begin to understand the meaning of the experience for that person. Yet similar challenges arose which made it difficult to counsel a person at home:

“...there is usually somebody on hand who does not want to leave...very...often the problem is that the person in the house does not want the nub of the problem to be mentioned, i.e., he is going to die...so there’s a lot of interference from other people clucking about with the necessities of nursing...to make sure the conversation is blocked...You need to talk about this person going to die and the other person...still got the language of hope...don’t want anything to upset him. It is often about stepchildren and...the child they might have had when they were very young...things...not part of the current partner’s life...the carer thinks...stirring up trouble and the sick one wants to say something” (Ormerod, 2010)³².

It was difficult to create an environment that would enable a dying person to talk about something they wanted to say when the carer did not share that philosophy. Similarly, home situations from which it was impossible to escape were also testing:

“I never fail to be shocked by the trappings of a sick room...you see the reality of the treacly clock ticking...tablets...nebulizers...still stuffiness of the world...can hear the dustbin men...people in the street and it is this kind of cocoon of slow...boring as hell silence...long glutinous maybe painful days. It is shocking. You go back out into the sunshine afterwards...It is hard to believe...I would look over my shoulders and think...who you know behind those doors, those curtains...so that I’d have to work very hard in trying to speak meaningfully to this person to get that to one side...particularly the younger ones...in their teens...again shocking sick kind of big pink teddies and huge get-well cards and sort of the trappings of jollity inevitable” (Ormerod, 2010)³³.

Here there is a glimpse into what it was like for some individuals as they neared the end of their life when they were unable to ‘live’ each day, and instead took on the role of a dying

person (hidden away) as a result of social negotiations in the home context. Sometimes those providing care were in denial, and this was evidenced by the get well cards and gifts. In these circumstances it was difficult for the counsellor to connect with that person to enable them to talk. Clearly there were many varied and complex needs, so it was important not to make assumptions but to find out how people wanted to 'play it'. The illustration overlaps with the importance of not putting ones views onto another person. Instead there was a need to get alongside them in order to do what they wanted. Such an approach also reflects the position of relativism in oral history because one view is not better or worse than another. Instead the researcher takes a neutral stance and acknowledges there are a range of perspectives (Fingerroos and Haanpaa, 2012).

Collaboration

The philosophy of practice brought the services together because it connected cancer services with support groups and palliative care facilities. Similarly social factors impacted to create much overlap between the services. A further example related to complementary therapy which was provided at the hospice by therapists from the cancer support services:

“...very much encouraged the liaison between the two charities...the aroma therapists would come down into the hospice” (Roth, 2010)³⁴.

In the early days these close liaisons were encouraged and it meant that complementary therapy provided by the cancer support service also formed part of the care at the hospice. Nevertheless, the availability of such therapy was very much down to the individual philosophy of the hospice matron at the time (Hopkins, 2010)³⁵. Therefore individual mechanisms impacted to shape practice because if perspectives valued complementary therapy it was offered, but if they did not then its availability was less likely. Yet some individuals might have found it beneficial but missed the opportunity of trying it. It highlights that there were so many differing views/needs; therefore it was important that individuals had the option to decide what was best for them. All of the illustrations so far contribute further to the ongoing story of the thesis that local services developed in a *tripartite* way and were very flexible in the beginning, like the evolution of technology (Pinch and Bijker, 1984).

5.3.2 Compassionate underpinnings

This section explores the meaning of compassion and how participants provided compassionate care. There were five key elements identified in relation to the provision of compassionate care: being alongside, intimacy, selflessness and confidence, compassion came from the top and could be helpful to those suffering ‘soul pain’. I will now describe each one in more detail.

Being alongside

The first point to make is that compassionate care had different meanings for different people. Susie Roth identified that compassion encompassed caring for a person ‘on their terms’:

“...I was thinking how can I make things better for him...Aine...said, ‘How are you’...I said...‘I’m caring for Mr...he’s so grumpy...I’m really trying so hard to smooth him over and help him come to terms with everything.’...Aine...said, ‘...why would you want to take his grumpiness away from him?’...that was a real learning experience...it was a wonderful thing...that really informed my working practice, to do with meeting the person where they’re at, for who they are. Up until then...I’d been...a bit of a ‘do gooder’...” (Roth, 2010)³⁶.

It was common for the rational mind to impose its linear perspective onto someone else in an attempt to make them ‘feel’ better. Nicolson and McLaughlin (1988) found that different medical groups tended to view the aetiology of multiple sclerosis from the perspective of their specialty. Yet in the course of time participants learned that it was important to meet a person ‘where they were in life’, for ‘who they were’ if care was to be compassionate. There was a requirement to be able to see that a wide range of perspectives existed because people with cancer and palliative care needs were a heterogeneous group. Moreover, if participants were able to do this then they could be ‘alongside’ someone by doing what the person wanted rather than what the professional thought they needed. That was really the essence of compassionate care. It was one of the biggest changes at the time because as explained it was not normal to put the patient at the centre, or attempt to ‘see’ things from their point of view. Nonetheless, before any of these things could be achieved it was essential to have courage:

“...some nurses found this hard...some may not have even found the courage...necessary to care for...dying patients and their families...you need courage...you need honesty...I was caring for a gentleman...he looked at me and he said, ‘Am I dying?’...I said, ‘...you are beginning to be dying.... You may not die tonight...you may not die tomorrow....But yes, this is what dying is like...a changing situation, the body’s changing.’...I said, ‘Are you frightened?’...he said, ‘No, no I’m not frightened...I’m glad you told me the truth.’...we walked out of caring for that gentleman (SR crying) and the nurse I was with said, ‘Oh, I don’t think I could have done that’...it’s really important to be honest with people...his question had a great clarity about it. Sometimes it isn’t as clear as that as to what people want...it’s to do...with the practitioner, this is my philosophy...really being prepared to be alongside their patient in wherever the patient’s at...” (Roth, 2010)³⁷.

Courage and honesty were needed in order to construct the ‘reality’ of a situation if that was what an individual wanted, however it was necessary to listen carefully in the first instance in order to find out (Saunders, 2000). Firth-Cozens and Cornwell (2009) held a workshop with National Health Service workers to discuss what prevents/enables compassionate care, and they suggest that it includes honesty and may also require courage. There was also a need to appreciate the impact of culture on perspectives and not make assumptions. People wanted different things and my interview accounts suggest that a compassionate philosophy was about being able to practise palliative care in a way that provided what the individual needed. Cornwell and Goodrich (2011) argue that a compassionate care giver never stereotypes but appreciates difference. My study shows that a degree of social negotiation had to take place in order to ascertain what a person wanted. Furthermore, it suggests that wider social mechanisms impacted to shape the way palliative care was provided because practices were constructed according to what was wanted/needed. Similarly, Gill Ormerod described how valuable a non-judgmental approach was when providing counselling:

“...people urgently wanted to address the fact that they were adopted or...always hated their partner or...have gotten into an extramarital relationship, or...loathes one of their children...something that had been...gnawing away...in them for maybe a lifetime...so there was a focus now that I must find a way to have it said before I die...I could convey with complete lack of judgment for there go I...I have

never heard the grubbiest story that I have ever thought, ‘Oh, fancy that!’...I have...thought what leads to that, where are you just going in life if there is where you end up...but I never thought it could not be me” (Ormerod, 2010)³⁸.

The philosophy behind compassionate care was also about being able to empathize and think about how one would feel in similar circumstances. There was a need to try and see ‘through the eyes’ of those with cancer and individuals approaching the end of life (Fall, 2010)³⁹. The reflective notes that I made during the interpretation and analysis of this account indicated how similar I thought the philosophy was to the methodology underpinning my study. In my research there was a need to ‘see’ through the lens of each participant in order to uncover how cancer and palliative care services developed (Thomas et al., 2009). The oral history insinuates that compassionate practice was similar because the participants endeavoured to ‘see’ from the patient’s perspective. Furthermore, compassion was also about having a desire to understand experiences from the family’s perspective:

“...young family...they had a very disabled child...they came in desperation...to Aine and said, ‘We would like respite care.’...Aine said, ‘Of course we will have this child.’ Well, then...the Inspector came and said, ‘...you’re not registered to have a child.’ And she said, ‘Oh, they needed it.’ And that’s great; she was that kind of person...” (Roth, 2010)⁴⁰.

Here we get a glimpse into how Sister Aine worked ‘alongside’ this family as an advocate in an attempt to meet their needs. They were desperate for respite care so she ensured it was provided, and that was more important than complying with the rules because the family was in crisis. They needed help at once, yet the hospice was not registered to take a child. In addition, compassionate care was also about ‘making the time’ to enable a person to achieve goals that were important:

“...the hospice rang...this gentleman here...we were hoping we would have a driver to take him out and there was nobody...his prognosis is poor is there anybody at CancerCare who can help...So I took him...they said he would like to go to his place of work and say cheerio to his mates...he said ‘Oh yes, Malcolm McIlmurray, nice man...He’s told me if I want a brandy with dinner every night to have one he said have two if you want them’, and he was clearly very aware of his

situation...and I sat in the car, wound the window down and I could hear him meeting his mates and there were expressions like ‘We’ll see ya,’ ...They couldn’t sort of come to terms with and...(DH sobbing)...his boss didn’t come out to see him...and then we got back in the car and he just broke up, you know, he should have, it was desperate that” (Hopkins, 2010)⁴¹.

Collaboration between CancerCare and the hospice helped a dying man achieve his goal to say goodbye to colleagues who had played a significant part in his life. There were no voluntary drivers available at the hospice so the General Manager of CancerCare stepped in to take him, and it was this level of cohesiveness that ensured the cancer and palliative care services were comprehensive. Participants had to be adaptable if they were going to ‘be alongside someone’ and help them achieve their goal:

“...some...would just call you over and say, ‘can I have one of those things with the wheels on.’ ...I used to think, ‘oh dear, what cheek,’ having come from...the normal sort of setup, but actually it was really good because whether or not I thought they needed a wheelie frame...was...irrelevant...because if it meant they could borrow one...and walk along the front at Morecambe, then it wasn’t my role to stop that. It was my role to facilitate it, but I had to learn that...because I hadn’t worked in that sort of way before” (Dalby, 2010)⁴².

A malleable approach enabled professionals to become more understanding of what a person needed, yet this was also something that was learned in the course of time. The underpinning philosophy assisted participants to ‘see’ an individual’s goal in the broader context of his or her life. In the illustration the person described might not have had a perfectly sized walking frame but that was not important, what mattered was to enjoy the pleasure that came from doing something they wanted to do. When one respected the fact that there was a spectrum of opinion it was then possible to start to understand the kind of care individuals wanted:

“I became increasingly confident to just be with the patients and go with what they needed...rather than taking my agenda...when we went to see this man...all he wanted to do...was talk about his wife...how long they've been married and how he loved her...Sue and I...used, squandered some might say...our 40 minutes of expensive professional time kneeling on the floor beside the bed with him holding

our hands, telling us about his wife...it...just would have been an insult really to get him out of bed and say you have to zip off...I could do that with Sue because I completely trusted her judgment and she completely trusted mine...I have no feeling that she would think 'Oh well, Leah is not doing her job'...that was what was right for him then..." (Dalby, 2010)⁴³.

When staff learned what individuals wanted they then had the confidence to go with the patient's objectives. Eventually this way of working became the consensus and shaped the practice of others, which was similar to the second stage in the development of technology (Pinch and Bijker, 1984). Furthermore, having faith in colleagues was important, there was concern that some might have considered the physiotherapist was not doing her job if there was a departure from usual practices. Soothill and Thomas (1998) uncovered a degree of defensiveness in respect of unconventional practices amongst those involved in cancer services. Therefore the account suggests that trust was needed in order to be able to go beyond the boundaries of tradition. These illustrations show that compassionate care was about supporting people in the manner in which they chose; Gill Ormerod summed it up as having the ability to 'dance the tune somebody wanted to play':

"...people with...unfinished business...what's going to happen to my dog...splitting my estate when one son is estranged...or really horribly, commonly, women exclusively...who have been in very cruel relationships...who keeps it covered...several women...just needed me to know...(pause) hairs standing up on my arms...people who are actually jailed at home...people who have had their child taken away and adopted because...the father did not want a child. Those have been some of the closest relationships because...it's urgent. It is...whispered...he's coming change of subject...I feel as though one of the things I...could do...was just dance to the tune somebody wants to play...as long as it is not collusive and silly...why not!...That is what somebody needs...just witness something before someone dies and they know it has not gone to their grave with them...I have worked with people...who are...coming and going...talking just frank about it rather than pretending everything is...normal. I have met people who are more or less fighting their eyes open because they want to say..." (Ormerod, 2010)⁴⁴.

There was a need to provide counselling right up to the very end because some individuals had things they needed to off load but were unable to do it until the final stage. Here oral

history also exposed unequal social, economic and gender issues between some men and women, which impacted on how the counselling/supportive services were provided. When necessary this was done covertly and the hospice provided a form of refuge where issues could be discussed safely.

Intimacy

Compassion also required a breaking down of the usual hierarchy so that individuals were on a more equal playing field. In the earlier illustration the General Manager valued such an approach and was prepared to double up as the ‘voluntary driver’ so that the person could say his farewells. This kind of intimacy was needed to create the ‘right’ environment and level of confidence to enable individuals to be open and talk in the first instance (McIlmurray, 2010)⁴⁵. It was also necessary to relate to people:

“...not very professional to say...‘do you think we've clicked?’ (Laughs), but people that I was seeing understood what that meant...” (Goad, 2010)⁴⁶.

It was important to ‘find the right person for that person’ to create the necessary level of intimacy (Roth, 2010)⁴⁷. This sense of intimacy strongly featured in Cicely Saunders’ writings on her relationships with patients (Saunders, 1965; Saunders, 1974; Saunders, 2000; Saunders, 2003).

Selflessness and confidence

The philosophy embraced the need to ‘talk to the person about the person’, which required selflessness on the part of the therapist as Jim Fall, hypnotherapist explained:

“...it’s about that sense of well being, about being calm...having a...sense of spaciousness, which is...when things happen. It...has to travel through that space...the outdoors for a lot of people is where they get that sense of connection which is beyond themselves...when you’re on a mountain and you look down, people look very, very small...all the stuff that looms so large in your life – houses, cars – they look quite tiny...You have a different perspective...so we started off walking...once a month...it used to have quite a strong...therapeutic side to it...I was available...really very moving at times...woman burst into tears...she had

been sitting by that loch in that place 10 months before with her husband...who had subsequently died...at home...it wasn't a nice death...she told me all about it...she was comfortable...it's a moment of catharsis...that opportunity...It really does help...to have a living presence...It might be a therapist, it might be a friend...somebody who's going to let you do it...really fall apart but not let you go to pieces so you can't come back together again...somebody with enough confidence to let it happen and that was the paramount" (Fall, 2010)⁴⁸.

We see here a need to create a sense of well-being to facilitate conversation, suggesting that walking was therapeutic because it enabled people to experience the impact of nature in the broader context of life on their past experiences. This created the 'space' necessary to enable discussion to take place about the deepest pain if that was what a person wanted. It was also necessary to have the self-assurance to enable a person to release all the 'bottled up' emotions and provide support so that they did not totally lose control.

Compassion came from the top

The oral history interviews indicated that there was a need for those leading the team to be compassionate because then the team was gentler with the patients. If the leader was brusque and did not 'see' compassion as an important quality, then the team tended to be sharp (Dalby, 2010)⁴⁹. A key requirement for compassionate philosophy was that it had to emanate from the top; it would then cascade through the team and ultimately pervade practices (Firth-Cozens and Cornwell, 2009). Nevertheless, some did not share this view at a later time:

"...we would meet with the...nurse manager once a month, who hadn't a clue about what we were about...they brought it in that every bit of your day had to be accounted for...The time...sheet...Probably about '93, '94, and on this particular day I said...'Where do you put compassion?' And she said, 'Compassion doesn't pay your wages' (Maguire, 2010)⁵⁰.

There were tensions at times in relation to different perspectives on what aspects of care were valued. The illustration shows that individual mechanisms impacted to shape services because some understood compassion but others did not appreciate its contribution to terminal care (see chapter 6).

Soul pain

Compassionate care was needed to bring comfort at times of particularly complicated distress:

“...you need someone who...understands and can put their arm round you...give you a...cuddle and reassure you in some way...you could help them in a more holistic way...you had to be aware...that there’s more to pain than just the physical cause...I remember lying on the bed...people...needed to be comforted...They were petrified...you think you’re going to die and it’s very frightening” (Shepherd, 2010)⁵¹.

Flexible compassionate approaches enabled individuals to reach out and provide some comfort to those who suffered complex pain – described as ‘soul pain’ (by Aine Cox, Matron of St John’s Hospice) which analgesia could not touch:

‘Medical science has advanced a long way in helping to control physical pain. But there is a deeper...personal pain that is not so easy to deal with...soul pain is not so easy to describe...All of us have so much in us...The mighty ship that sails on the water can only be seen moving majestically because of that part of the ship that is under the surface. Yet it is in that hidden place that the power to move is contained. The physical outer part...is easily seen, not so that part of us that lies under the skin – our spirit or soul...where we tick and...where we really hurt...speaking with someone in soul pain is like trying to operate on a level ‘under the skin’...scary, unknown, painful territory...Our only response must be one of...silence – emptiness, total attentiveness...a listen with the heart...with...love, respect and above all compassion. So often we listen with our head – judgmental, critical...Rather...be patient and allow the other person to be himself...the pain is not something limited to the present. It reaches back with countless tentacles into the experiences of past years...the sufferer may not know...where the deep source of his pain lies...the only worthwhile contribution one has to give is to listen with a heart full of compassion – to attempt, with his permission, to walk along his road of pain...alert to every nuance...expression of feeling, listening to what he is attempting to express as well as to what he is afraid or unable to express’ (Cox, no date, p.983)⁵².

The illustration portrays the meaning of ‘soul pain’ for the carer and the person suffering, and some of the elements were evident in the oral history of participants in my study. The key skills for carers that were identified as being important involved learning to listen, creating space and accepting people for who and where they were in life. Soul pain was found to occur when an individual became cut off from the deepest parts of him/herself. There was a sense of alienation and meaninglessness. Kearney (no date) found that the locus of control that enabled healing was within the patient. The care giver did not heal the patient – he/she facilitated this process by providing a secure environment grounded in a sense of connectedness. It was this connectedness with the soul that could bring wholeness and a sense of significance (Cox, no date; Mount, Flanders and Kearney, 2003). There was a desire to gain a deeper understanding of the experiences of those nearing the end of their lives. Consequently, in 1987 discussions between Malcolm McIllmurray and the Master of Sculpture at the Royal Academy led to the idea of ‘an artists in residence’ scheme. The plan was to explore sculpture as a means of communicating feelings, and to help individuals understand more about their reactions to terminal illness (McIllmurray et al., 1992). The experiment assessed the effect beneficial or otherwise, which it had on the patients, staff and visitors. The ten week project was funded by the Forbes Trust and evaluated by the Public Art Development Trust, King’s Fund and Sociology Department at Lancaster University. The chairman of the Forbes Trust was willing to fund similar projects in other hospices if it was found to be beneficial (Caudrey, 1987; The Beacon Fellowship, 2008).

Subsequently, the bathroom at St John’s Hospice was turned into a ‘surreal sanctuary’ where some of those nearing the end of their lives sat naked, physically and emotionally. Sculptors Benthe Nordheim and Jim Thrower worked amongst them to embody ‘...the fears, memories and visions of people at the most critical point in their lives’ (Caudrey, 1987, p.14). Some individuals bared their soul pain and the sculptors tried to give form to that inner state. The artists were asked to create their own work; individuals were not expected to participate so it was not ‘art therapy’ in the usual sense (Frampton, 1986). The project was evaluated qualitatively using ethnography and interviews. A general view was that it made little impact on the majority of inpatients. However for those well enough to follow the project it provided excitement, interest and an opportunity to talk about what they were going through. Some day patients were indifferent to the project and a few were hostile, they disliked the sculptures and preferred to see ‘nice’ pictures or the flowers which were normally on display.

One reason for the difference in reaction compared to inpatients could have been that they had less contact with the sculptors, and the purpose of the project had not been explained to them. Another possibility was that they were not so accepting of death and dying and resented being confronted by it in the sculptures. The sculptures had a profound effect on some visitors who were able to use them to ‘...introduce their own feelings of loneliness, grief and fear’ (McIllmurray et al., 1992, p.37). Similarly, permanent staff reported that the greatest success of the project was it served as a starting point for discussion. However, there was tension because some volunteers thought that the hospice should be ‘...bright, cheerful, colourful and welcoming...patients should be protected from things challenging, threatening or confrontational’ (McIllmurray et al., 1992, p.37). The example indicates that some minds were not open to considering differing philosophies/approaches to terminal care. Consequently, they did not think it was a good idea to unlock experiences of end of life issues, yet there was ‘...powerful evidence...’ (McIllmurray et al., 1992, p.38) the project greatly benefitted a number of people and the effects were long-lasting. For example, it brought dying out into the open by using the sculptors to reflect the experiences of those in the final part of their lives:

“Aine was broadminded in many ways...fine skeletal representations...showed people dying in excruciating pain. They were representations, but very symbolic of the cancer process...artists would talk to the patients...then...make these representations and there was a lot of controversy...volunteers (laughter) were a strong body...a lot of them thought this was horrific. They didn’t want it to be on display...they just thought it was too...raw for patients to be even more terrified by...they were put away in a small room...Aine would take people who wanted to, to see them...I thought – here is somebody with an open mind who is really trying to understand a bigger picture of death and what it means to our society” (Bulman, 2010)⁵³.

It was important to be open to a range of perspectives in order to begin to understand more about individual experiences. Yet, some volunteers thought people would be terrified if they were confronted by ‘dying’ in the sculptures and they tried to protect patients. The oral history provided a glimpse into some of the individual and cultural structures that impacted on the way in which cancer and palliative care services developed. Here concerns for patient’s wellbeing and the imposition of one person’s perspectives onto another

person's, led to the sculptures being hidden away because they were too controversial for some. Yet ironically they were representations of patients' reflections.

The following year in 1988 Lynne Alexander became the 'writer in residence' at the hospice; the idea came from Terry McCormick, Resident Curator for the Wordsworth Trust in Grasmere. He had become involved with 'St John's Literature Project' at an earlier time when his son had leukaemia. The project enabled patients, relatives and staff to '...put into words what they felt but didn't dare or know how to say' (Alexander, 1990, p.14). Poems were created to express experiences of cancer, multiple sclerosis, death and dying. This led to the publication of a book called 'Now I Can Tell' (Johnson, 2010)⁵⁴. Both the sculpture project and the writer in residency were also used to give those providing cancer and palliative care a greater understanding of the meaning of the experiences of those nearing the end of their lives. This section uncovered some of the elements that were required to make care compassionate, those who had the ability to be 'alongside' individuals had an opportunity to provide some of the most useful care.

5.4 Summary

This chapter has uncovered the philosophy of care and practice of the participants who set up local cancer and palliative care facilities. These services were in part shaped by historical experiences; some participants drew on personal encounters to help them deliver *tripartite* services (McIllmurray, 1992b; McIllmurray et al., 1998). Social mechanisms also impacted to make the facilities collaborative; there were many links between the participants and the services. The reflections exposed wider social and economic inequalities between some in the community; these in turn affected the manner in which services such as counselling were provided.

The accounts revealed some very personal stories which make a contribution towards understanding more about the intangibles of compassionate care, and how people were looked after as they neared the end of their lives (see discussion below). In doing so it builds on the knowledge generated in chapters 3 and 4 by answering the research questions about philosophy of care, complementary therapy, bonds between organizations and charisma. Therefore, it goes a step closer to addressing the aims of my study. For example, the accounts embodied elements of social constructionism to reveal that the *tripartite* services were flexible in the beginning. Yet they became more structured in the course of

time as consensus emerged to limit interpretative flexibility, and confirm what was considered to be an acceptable service, in a similar way to stabilization of technology in the SCOT (Pinch and Bijker, 1984). Therefore the chapter addressed the first aim - 'to ascertain how individuals developed cancer and palliative care services in one community'.

Moreover the oral history showed that compassionate care practices also resonated with a similar methodology to that used by Pinch and Bijker (1984) because protagonists challenged the rationality of conventional mechanistic approaches. These had been problematic because they focused on physical disease at the expense of psychological issues. The proponents of the local services understood that there were a range of viewpoints in cancer and palliative care, these might differ to the 'professional's' but one way was not necessarily better than another. Nonetheless in order to care for the whole person and address emotional distress, which was just as 'real' as physical problems there was a need to understand what a person wanted. Such issues were highlighted by Saunders (1965) who established that there were psychological, social and spiritual dimensions to pain and distress. Yet the accounts suggest that the participants also understood that a person might want holistic care, but some might not. A search of the literature reveals that little has been written on philosophy and compassion in palliative care. There is a chapter written by Professor Philip Larkin in a book edited by Irene Renzenbrink published 2011 on compassion. 'Compassion provides the unspoken language to address unspeakable suffering' (Sasser and Puchalski, 2010, p.937, cited by Larkin, 2011, p.155). Larkin acknowledges that 'compassion' is under-researched in palliative care. He underscores that it is important to describe and interpret what compassion means in the context of death and dying, and how it underpins the approach to the care of dying people. There is a need to have the ability to 'embrace stillness and silence...compassion arises from the ability to use that heart wisely in caring for others...' (Larkin, 2011, p.165). 'Compassion assumes we have regard and respect for another human being, that we hold concern for the welfare of others, are aware of the nature of suffering, and have a desire to relieve that suffering if at all possible' (Bergum, 2004; Bregum, 2003; Pask, 2003; Blum, 1980, cited by Larkin, 2011, p.159). Compassionate care practices in the *tripartite* services were uncovered in the accounts and these have been described. Furthermore, participant's viewed the patient as the expert, which was unusual at that time because generally the patients would have been expected to fit in around conventional routine. Yet here the underpinning philosophy of the participants tried to 'see' the wider picture of dying from the individual's perspective. I

also achieved the second aim of the study – ‘to capture experiences of how care was provided at the end of life’.

Overall, the chapter has moved the reconstruction closer to addressing the overarching research question to show how cancer and palliative care services developed at the local level, at a particular time. I will now move on to the final empirical chapter which looks at some of the struggles which arose in the course of time, and how these were addressed by charismatic individuals.

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- ¹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ² Carne, C. (2010). Interview with Sara Denver in Farleton on 12 November.
 - ³ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ⁴ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ⁵ Shepherd, M. (2010). Interview with Sara Denver in Hornby on 6 September.
 - ⁶ Shepherd, M. (2010). Interview with Sara Denver in Hornby on 6 September.
 - ⁷ Warren, M. (2010). Interview with Sara Denver in Lancaster on 12 July.
 - ⁸ Warren, M. (2010). Interview with Sara Denver in Lancaster on 12 July.
 - ⁹ Ellam, M. (2010). Interview with Sara Denver in Lancaster on 21 September.
 - ¹⁰ Williams, T. (2010). Interview with Sara Denver in Hest Bank on 11 May.
 - ¹¹ Lomax, R. (2010). Interview with Sara Denver in Lancaster on 22 April.
 - ¹² Hunt, J. (2010). Interview with Sara Denver in Kelleth on 19 October.
 - ¹³ Ellam, M. (2010). Interview with Sara Denver in Lancaster on 21 September.
 - ¹⁴ Warren, M. (2010). Interview with Sara Denver in Lancaster on 12 July.
 - ¹⁵ Ormerod, G. (2010). Interview with Sara Denver in Levens on 26 August.
 - ¹⁶ Bulman, S. (2010). Interview with Sara Denver in Brigsteer on 18 May.
 - ¹⁷ McCaldin, M. (2010). Interview with Sara Denver in Stocksfield on 9 September.
 - ¹⁸ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ¹⁹ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
 - ²⁰ Shepherd, M. (2010). Interview with Sara Denver in Hornby on 6 September.
 - ²¹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ²² Shepherd, M. (2010). Interview with Sara Denver in Hornby on 6 September.
 - ²³ Bulman, S. (2010). Interview with Sara Denver in Brigsteer on 18 May.
 - ²⁴ Warren, M. (2010). Interview with Sara Denver in Lancaster on 12 July.
 - ²⁵ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ²⁶ McCaldin, M. (2010). Interview with Sara Denver in Stocksfield on 9 September.
 - ²⁷ McCann, C. (2010). Interview with Sara Denver in Grange-over-Sands on 5 October.
 - ²⁸ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ²⁹ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellett on 25 May.
 - ³⁰ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
 - ³¹ Bulman, S. (2010). Interview with Sara Denver in Brigsteer on 18 May.
 - ³² Ormerod, G. (2010). Interview with Sara Denver in Levens on 26 August.
 - ³³ Ormerod, G. (2010). Interview with Sara Denver in Levens on 26 August.
 - ³⁴ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
 - ³⁵ Hopkins, D. (2010). Interview with Sara Denver in Lancaster on 23 November.
 - ³⁶ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
 - ³⁷ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
 - ³⁸ Ormerod, J. (2010). Interview with Sara Denver in Levens on 26 August.
 - ³⁹ Fall, J. (2010). Interview with Sara Denver in Lancaster on 9 November.
 - ⁴⁰ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
 - ⁴¹ Hopkins, D. (2010). Interview with Sara Denver in Lancaster on 23 November.
 - ⁴² Dalby, L. (2010). Interview with Sara Denver in Melling on 19 July.

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- ⁴³ Dalby, L. (2010). Interview with Sara Denver in Melling on 19 July.
- ⁴⁴ Ormerod, G. (2010). Interview with Sara Denver in Levens on 26 August.
- ⁴⁵ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellett on 25 May.
- ⁴⁶ Goad, M. (2010). Interview with Sara Denver in Lancaster on 14 October.
- ⁴⁷ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁸ Fall, J. (2010). Interview with Sara Denver in Lancaster on 9 November.
- ⁴⁹ Dalby, L. (2010). Interview with Sara Denver in Melling on 19 July.
- ⁵⁰ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.
- ⁵¹ Shepherd, M. (2010). Interview with Sara Denver in Hornby on 6 September.
- ⁵² Cox, A. (No date). Sharing in soul pain. Talk Aine Cox gave to the Samaritans in York. Provided courtesy of Brenda Farrar.
- ⁵³ Bulman, S. (2010). Interview with Sara Denver in Brigsteer on 18 May.
- ⁵⁴ Johnson, P. (2010). Interview with Sara Denver in Lancaster on 8 November.

CHAPTER 6

STRUGGLES, CHARISMA AND CONNECTED NETWORKS

6.1 Introduction

This chapter provides more details about the conventional practices that participants experienced in other places around the country before they began to create cancer and palliative care services in Lancaster. It shows how they brought the learning that they had previously acquired to the Lancaster setting, and how this impacted on the development of services there. It also identifies the local struggles that arose - for example chapter 4 revealed that policy came from the grass roots at a time when ‘...there were no counselling, cancer services or facility providing terminal care’ (McIllmurray, Gorst and Holdcroft, 1986, p.670). This appeared to make it easier to develop new services rather than change existing ones (Youren, 2010)¹. Yet the pioneers’ heterodox philosophy acknowledged that psychosocial problems were as ‘real’ as physical problems, and this created tension at times (Roth, 2010²; Youren, 2010³). This chapter reveals how individual factors such as charisma and social networks enabled the proponents to overcome these difficulties in order to develop the *tripartite* services. It shows how some of the protagonists used positive examples of their practices to demonstrate the value of their work. When the palliative care services became more specialized different struggles emerged and these are also explored. For example, some of the historical approaches that had been used to provide hospice care did not fit with the ideas of those providing specialist services. Furthermore, specialist care brought expertise and the need for greater formalities; these created new challenges which are also investigated. Finally this chapter examines the difficulties that emerged in relation to appraising the cancer and palliative care services.

The research findings will be placed in the wider context of cancer and palliative care issues to increase our understanding of change in the relevant period. Overall, this chapter will address aim one – ‘to ascertain how individuals developed cancer and palliative care services in one community’, aim three – ‘to place the research findings about service

development in the wider context of cancer and palliative care issues’ and aim four – ‘to increase understandings about the development of cancer and end of life care provision over time’. In achieving these aims it will make a further contribution to the overarching story of the development of local *tripartite* services. I start by exploring the participant’s early experiences to illuminate the impact these had on the development of local services.

6.2 Historical mechanisms

I have explained that the pioneers were multidisciplinary, the Cancer Support Nurses had considerable autonomy, and the philosophy acknowledged that psychosocial problems were as ‘real’ as physical problems (see chapter 4). Yet this approach created some strain in the early days, and there were four key historical elements identified which provided background context to this tension. First, conventionally health care services were very hierarchical (Hockey, 1977; Maguire, 2010⁴):

“...training...was...a bit shocking...hospitals were very, very institutionalized places...very hierarchical...very clear roles as to...the consultant, the doctor, the entourage which goes round with the ward round...if one was an enrolled nurse status...‘Nurse, stop doing what you’re doing, go and clean the sluices’ (Roth, 2010).⁵

Those at the pinnacle of the hierarchy, the medical profession were the most influential and could be difficult to challenge (Shelley, 2010)⁶. Lisbeth Hockey, pioneer of nursing research also described ‘...a...nursing hierarchy, with momentous responsibility for decision-making...at the apex...and simple task-orientated care at its base’ (Hockey, 1977, p.150). Yet in the overall structure Hockey was never impressed at the way doctors lectured student nurses with much ‘diluted medicine’, and ward sisters discouraged her questioning (Dopson, 1985; Dopson, 2004). Accordingly, she always encouraged nurses to challenge the existing state of affairs (Tschudin, 2002). Those I spoke to suggested that nurses were not generally encouraged to question convention. Second, accounts suggest that it was not usual for those practising medicine to provide psychosocial care because the

medical paradigm focused on disease and physical problems (Kearney, 1992; McIlmurray, 1997; McIlmurray and Holdcroft, 1993). It was not common to tell a person about their condition/circumstances in an attempt to reduce anxiety (see Mike Warren's oral history in chapter 4). Similarly the study by Mills, Davies and Macrae (1994) found that staff avoided talking to dying patients. These historical approaches were also identified in the study '*A Bit of Heaven For The Few?*' Colin Murray-Parkes identified a culture where doctors handled very distressed patients by distancing from them; he formed a view that this '*...was being used as a defence to prevent the doctor getting too emotionally involved...*' (Clark et al., 2005, p.21). It has also been suggested that this was done to dissuade awkward questions about cancer or end of life issues (Maguire, 1985). Nonetheless, my study found that some participants questioned such practices because they thought talking was a good idea, even though it was difficult due to lack of time and because such change did not 'fit' in with the usual pattern (Roth, 2010)⁷. Similarly, other participants realized that despite the custom requiring people to accommodate to the system, there was a huge need to treat people as individuals. For example, when Millie Shepherd went to work in oncology in the early 1980s care was not individualized, people had to fit into the routine and attend for chemotherapy at the same time. The day became known as 'black Tuesday' because everyone was kept waiting, when they could have been with family and friends (Shepherd, 2007). When social constructionism principles were applied to traditional approaches revealed in the accounts it was possible to see that the practices were rational (Pinch and Bijker, 1992). There was but 'one way' and everybody including patients were expected to follow it.

However, in the criticisms of these approaches we can also see that those who eventually went on to develop cancer services had a desire to care for the individual person in a holistic way. Lisbeth Hockey argued that one of the reasons for going into district nursing was because she did not have to '*...separate people into parts*', in the hospital she felt worried about '*...not being able to deal with people as whole beings*' (Dopson, 1985, p.17). Yet the main problem for participants was that the approach of the most powerful group was linear, and as I have explained it focused on disease (Kearney, 1992; McIlmurray, 1997) (see chapters 2 and 3). Accounts suggest that those who privileged traditional approaches found it difficult to see the value of cancer support services and complementary therapy (see chapter 4). It appears likely that those who had undergone traditional medical training would conceive care in rational 'medical paradigm terms'.

Consequently, the theory on care would most likely be biomedically localized as Nicolson and McLaughlin (1988) found in work on Multiple Sclerosis. Following the thread of this argument, it suggests that those who had been trained to follow the medical model would be more likely to perceive the services in biomedical structural terms, but they were radically different:

“...CancerCare side took longer to develop...because...people could not see any use for it...It’s difficult to describe...without making myself seem very...tough... When resources were given to...having massage sessions or...flower arranging...clubs meetings...Hospice, yes; CancerCare, no...” (McKinney, 2010)⁸.

The oral history of Hugh McKinney, retired General Practitioner uncovered tensions that existed on the other side of the controversy as a result of different viewpoints, and some individuals could not see a role for complementary therapy to treat emotional distress. In the wider context, on the subject of the allocation of resources for emotional needs, Hockey also observed that society accorded low priority to mental distress generally (Hockey, 1977). Similarly accounts on philosophy in chapter 5 suggest that in the early years little value was placed on ‘talking’ as a means of addressing emotional needs. Consequently, the cancer support service was met with much scepticism in the early days (Rouncivell, 2009). There were a great many challenges to overcome because complementary therapy was a new idea, it did not fit in with traditional ways and many were suspicious of it (McCaldin, 2010⁹; Youren, 1996; Youren, 2010¹⁰). Complementary therapists came from a marginalized and weaker group than those in conventional positions. It was more difficult for them to develop the cancer support services as many were from less traditional backgrounds, and they lacked qualifications/resources to make their case. Their holistic approaches competed with more powerful paradigms. I have explained that the key problem here was the burden of persuasion lay heaviest upon the proponents of the cancer support services (as it did for those in hyperbaric medicine described by Nicolson and McLaughlin, 1988). Furthermore, those who privileged conventional ways had no interest in embracing change, this kind of resistance has been described as ‘...the most common and possibly the greatest hindrance to progress. The challenge lies in seeing the potential of new ideas and to consider change if it is justified and defensible’ (Hockey, 1980, p.910).

The third reason identified as to why there was some tension was because people were unhappy about the lack of facilities, and the way they had been treated before the local cancer services existed:

“Cancer Self Help Group Conferences...that was a patient led initiative...the first one, you didn’t want anyone to know if you were professional...there was SO much anger about, patients were SO unhappy, SO annoyed...it was pretty awful” (Youren, 2010)¹¹.

The annual National Conference of Self Help Groups in Manchester was started by CancerLink in 1984, around the same time as services were getting underway in Lancaster (McCaldin, no date; National Conference of Cancer Self Help Groups, 2012). Increasing expectations from a better informed public, coupled with anger about the lack of services locally became apparent at the initial conference (Youren, 2010)¹². The hostility directed at professionals stemmed from a combination of negative experiences of the conventional hierarchical system and lack of services. It made delegates from Lancaster feel uncomfortable about the fact that they were also “professionals” (Youren, 2010)¹³. Of course these pressures did not exist in a vacuum, there was a much wider ‘...growing militancy within the general public about the lack of information and choice available...by health care professionals, not just the cancer treatment systems’ (Youren, 1996, p.5)¹⁴. Similarly, Watson and Woods (2005) found that pressure groups made demands on the health board, which influenced those working on wheelchair seating for people with learning disabilities and/or severe physical impairments. There was also dissatisfaction in the lack of services and a growing awareness of the need to provide better care.

It was against this background of historical and social frustration that individuals realized there was an urgent need for change and responded with the *tripartite* services which included cancer support, palliative care and oncology services (McIllmurray, Gorst and Holdcroft, 1986). In chapter 4 I explained that change occurred when there were stories that produced pressure, furthermore politics decided if the pressure was ‘bearable’ and the context decided the shape of response to that pressure, these components were evident in accounts (Small, 2003). Similarly when thinking about change it has been found in other settings outside palliative care, that it is essential to establish a ‘...great enough sense of

urgency' to make people realise that '...business as usual is totally unacceptable' (Kotter, 2007, p.98). Only then will sufficient pressure have built up to bring about change, and in my study the public had become increasingly more questioning of the lack of services and advice available. They were no longer accepting of the struggles and wanted more information and facilities. Consequently, the shift towards holistic services meant that people were being told about their cancer diagnosis/prognosis. Furthermore, the debate surrounding the need for better terminal care was also opened up. Nevertheless, whilst cancer support services eventually became firmly established as a resource for individuals, the family and bereaved it was not a smooth transition which leads on to the final main reason for the tensions (McIllmurray and Holdcroft, 1993).

Fourth, there were difficulties associated with establishing medical oncology and the cancer support nursing service locally, as historically individuals had differing levels of authority:

“...I met a lot of resistance...physician...was...hostile...to my appointment...didn't see the need for...medical oncology...he felt he was perfectly capable of handling...cancer problems...he was...powerful enough to have...written to me...he sent a letter...to all the GPs...saying that he thought this was a preposterous idea...unnecessary and...strongly opposed any of the clinicians setting up specialist clinics...” (McIllmurray, 2010)¹⁵.

Tension mounted because some individuals felt threatened by the specialist services and saw them as an erosion of their own power. The notion of 'paradigm wars' described by Oakley (1999) came to mind because routine practice was being challenged. In addition, those who did not support change could have been trying to prevent it to maintain orthodoxy. I have explained that medical oncology was relatively new compared to clinical oncology, and the latter was provided by radiotherapists in regional centres (Murphy, 1990) (see chapter 4). In addition there were wider social, historical and political factors impacting on the development of medical oncology at this time. By way of example, medical oncology had not had time to establish the same level of authority as traditional medicine because it did not have a 'professional body' representing its interests until 1985 (Association of Cancer Physicians, 2012; McIllmurray, 1987). Moreover, this meant that proponents needed to gather enough support to bring the services into fruition and make

them respectable. Change was only going to take place when sufficient pressure built up to create a paradigm shift, which did not happen overnight.

Similarly, the Cancer Support Nurses had started in the days before Macmillan was established to provide cancer support locally. Accounts suggest that wider social and historical mechanisms also impacted on the nurses' role and ultimately the services. The Cancer Support Nurses had more autonomy than they had previously experienced, but they had less authority than those in conventional medical positions. Some General Practitioners formed a view that cancer support was 'a community function' that could be handled by District Nurses, and it did not require any specialist input from Cancer Support Nurses (McIllmurray, 2010)¹⁶. Others were of a similar view:

“...district nurses...were, quite suspicious that someone was going to take a treasured part of their role...just one or two were very resentful of anyone who would think they knew something more than they did” (Maguire, 2010)¹⁷.

Some nurses were protective of their position because they were concerned about loss of control; they worked closely with General Practitioners who up until now had had the responsibility for those within their remit:

“I remember...saying I'm being reduced to washing bottles and changing sheets...it was a bit of a struggle” (Williams, 2010)¹⁸.

There were difficulties as some nurses felt that they were being deskilled by the Cancer Support Nurses taking on roles which they could have done:

“...the community staff were up in arms...in the end...we held...an information evening...Malcolm got them all in, locked the door and wouldn't let them out...until we had sorted out whatever the problem was and I can't even remember

what the problem was, it'll be territory...I've never understood that mentality...but it's very prevalent in all disciplines..." (Youren, 2010)¹⁹.

Pippa Youren strived to get her role accepted by those who felt threatened by the change. The illustration also implies that there was a sense of 'ownership' in the individuals who were being looked after, and some doctors thought they were being edged out by specialists. It was a perspective that might have had roots in the pre National Health Service period, when all patients were private and nobody wanted to lose them (Lomax, 2010)²⁰. The struggle was considerable:

"We did lack credibility with GPs...very resistant to nurses...It was...like walking through treacle...a lot of them were really...difficult...It was an uphill struggle (McCann, 2010)"²¹.

Some individuals did not value the higher degree of autonomy and responsibility enjoyed by the Cancer Support Nurses (McCann, 2010)²². Others were suspicious and questioned the benefit of Cancer Support Nurses, so it was a challenging job (Maguire, 2010)²³. All of these illustrations show that there was tension as a result of struggles taking place amongst the various roles, as the *tripartite* services disrupted conventional approaches. I will now move on to look at how these difficulties were overcome.

6.3 Negotiating the challenges

There were two mechanisms or 'solutions' detected that enabled individuals to overcome some of the struggles and develop *tripartite* services (in a similar way to the solutions to technological problems described by Pinch and Bijker, 1984, p.211): first, support from the top was needed as were links between social and historical mechanisms, and these are now considered in detail.

6.3.1 Support from the top

I have explained that sceptics from the more powerful medical group were initially problematic for those developing cancer and palliative care services. Yet similar historical and social mechanisms were also identified as the main reasons for the services being able to develop as and when they did. By way of example, the strategic positioning of the oncology consultant within the hierarchy described was a key factor that enabled the *tripartite* services to evolve:

“...that was unique...if the consultant had not been willing it wouldn't have happened...he was very open...” (Youren, 2010)²⁴.

“...we had such an advantage because our organization was...set up by Malcolm...that broke a lot of the early ground...other organizations...said...that was the key...which had made things easier...They met a lot of scepticism from the medical profession...having Malcolm and Pippa working with Malcolm...other doctors would...trust her judgment. That made all the difference...the particular success of the Lancaster Project was due to the fact that it came originally from a doctor. Without that...it would be very, very difficult... you have got to have a medic to head up your services... You need an important figurehead...” (McCaldin, 2010).²⁵

The support of the doctor, particularly in relation to complementary therapy was very important to developments because he had the power and status required to make the services respectable. It helped to overcome much of the resistance (Fall, 2010)²⁶. In addition, acceptance was likely to have been because the ‘perceived efficacy’ of the supportive/complementary therapy hinged on the relative political power of its supporters (as Nicolson and McLaughlin, 1988 found in their multiple sclerosis work). Therefore, it was crucial to have a doctor champion the support services because he was seen as socially influential. One of the main reasons Cicely Saunders retrained as a doctor was because she formed a view that doctors would not listen to ideas about terminal care if they came from a nurse or social worker (Saunders, 1974; Saunders, 2003). Similarly, outside the cancer and palliative care arena in the world of business management Kotter (2007) argues that ‘...major change is impossible unless the head of the organization is an active supporter’ (Kotter, 2007, p.98). It was also important to involve individuals with a range of views

because once on board they were more likely to be supportive. Therefore the pioneers were also strategic in the manner in which they gathered champions and promoted services:

“...we worked out a group of people and we thought we will get all these people together and we will ask them to be on the advisory group...we won't ask them to DO anything...we don't want them to DO anything...except be supportive...and pass on information” (Youren, 2010)²⁷.

Those in the wider community were made to feel that they were part of the new developments but at the same time they were given a limited role, rather than one where they had significant influence. They could have made things more challenging to the point of being disruptive with time had they not been involved. The approach enabled services to develop by keeping some on the margins whilst the protagonists remained in control, and this was an important charismatic feature of pioneers. James and Field (1992) argue that charismatic movements can only be successful if they ‘...resonate with tensions and ambiguities in the broader social context in which they arise’ (James and Field, 1992, p.1363). The participants appear to have had the ability to do this because they used persuasive powers to get a range of people involved in the organizations. Kotter (2007) found that in order to successfully bring about change the head of the organization, plus several others need to come together with a shared commitment to excellent performance. The group then becomes powerful as a result of titles, expertise, reputations and relationships. Accounts imply that the proponents of the local services provided the social kudos that was needed for the service to become established, and these social factors are now examined in detail.

6.3.2 Links between social and historical mechanisms

There were links between social and historical mechanisms which brought the proponents together and consequently impacted on the development of the *tripartite* services. Accounts indicate that it was important to recruit “...like minded” (Youren, 2010)²⁸ individuals because they had a similar ethos, which supported ideas about developing these facilities. Five main social and historical connections were detected as bringing the

participants together to develop cancer and palliative care services: marriage, friendship, past experiences, health visitor roles and choosing recruits and these are now discussed.

Marriage, friendship and past experiences

Many participants reflected on the links that there were between participants and how these impacted on developments:

“I came...to work at Cancer Care because my ex-husband...was a trustee...we were friendly with Malcolm and Geraldine McIlmurray and Meg McCaldin because I'd gone to her for NCT classes” (Howarth, 2010)²⁹.

Earlier experiences and social connections in other places drew some individuals into the cancer and palliative care services. For example, in the 1970s Meg McCaldin had worked as a relaxation therapist at the local National Childbirth Trust. This earlier work linked her to some of those involved in setting up the cancer and palliative care services, and she was asked to provide relaxation therapy to individuals with cancer (see chapter 4). It is remarkable to find there was a connection between broader social and historical structures and the National Childbirth Trust, which impacted on the cancer support facilities. There were other social links; some volunteers were drawn into the new services because they had husbands or wives who were already involved in the charities (Hearn, 2010³⁰; Hopkins, 2010³¹; McIlmurray, 2010³²; Warren, 2010³³). There were also bonds between participants that stemmed from previous work experiences in other areas (Hunt, 2010³⁴; Maguire, 2010³⁵; Roth, 2010³⁶; Warren, 2010³⁷). By way of illustration, Ellie Maguire had worked with Mike Warren in the district prior to becoming a Cancer Support Nurse and before Mike Warren became a hospice doctor (Maguire, 2010)³⁸. These connections stretched further back in time as Mike Warren had previously provided medical cover at St John of God Hospital (see chapter 4). In addition, Lucy Parker was associated with St John of God as early as 1968 when she was the Medical Social Worker in Kendal. It was to Lucy Parker that Brother Bernard of the Society of St. John of God had turned to say that the facility would have to close down unless a suitable successor could be found. Furthermore, it appears that Lucy Parker was instrumental in persuading the Sisters of Our Lady of Apostles to take over St John of God Hospital (Parker, no date)³⁹. Mike Warren corroborated this:

“Lucy Parker was aware of the Sisters...because she’d been intimately involved with their arrival there and they were very closely connected” (Warren, 2010)⁴⁰.

All of these accounts suggest that individuals came to be involved in the development of cancer and palliative care services through broader historical and social mechanisms, and these in turn impacted on the services developing in the way that they did at that time. This ability to focus on individual experiences, and link these phenomena to the wider historical and social mechanisms, was one of the key advantages of the oral history method used for this study (Portelli, 2006).

Links through health visitor roles: choosing recruits

Some Cancer Support Nurses and their colleagues were connected because they had also trained as Health Visitors or were married to Health Visitors:

“...he was actually married to a Health Visitor...and he was so supportive of me...what a boon for me... oh this is links upon links...” (Youren, 2010)⁴¹.

These earlier social and professional connections helped the cancer support services to develop because there was a shared understanding of the role of the Health Visitor. Consequently, there was perhaps a greater willingness by those who understood that role to accept the Cancer Support Nurse as many of them also had a background in Health Visiting. Furthermore, there was a close network of collaboration which appears to have been necessary to get ideas accepted. It might have meant there was less openness to challenge from the wider context. For example, whilst the new services were able to develop in line with the vision of the pioneers there were different viewpoints as the oral history revealed. Nonetheless, from the outset people were carefully chosen because they were perceived to have the necessary attributes to work in cancer and palliative care:

“...Pippa...a friend of hers...had...trained in massage...Malcolm...heard that I was doing a lot of relaxation work...he asked if I would be interested in doing some relaxation work with cancer patients...and...families” (McCaldin, 2010)⁴².

Having the requisite characteristics appears to have been a key factor in the services progressing and Pippa Youren “wanted the best of the best” (Fall, 2010)⁴³, so she met all the therapists to determine who was effective and who was not. I move on now to explore how some of the cultural difficulties were dealt with.

6.4 Negotiating cultural challenges

In this section I report on how cultural assumptions made in the early days needed challenging at a later period:

“...you didn’t get a...paid holiday, for the first year...there wasn’t a pension...that would have been to do with the fact that the...sisters...lived in a community...down the road...when they would retire, they would be cared for by their...community...employment law would probably oblige us to do something...we...paid people their holiday...it was a huge bill...staff of 80...It’s an example of the kind of...changes...that needed to be brought about” (Roth, 2010)⁴⁴.

Challenges arose for Susie Roth when she took up her post as Matron in 1994 because of assumptions that had been made when the hospice began. These reflected the needs of the Sisters who did not need pensions because the Order took care of them in retirement. Yet this created an unequal social situation for those who were not part of the Order because they were without holiday pay and a pension. Consequently, in the course of time broader legal requirements impacted to shape the hospice services (Roth, 2010)⁴⁵. The accounts also suggest that some individuals assumed that the hospice was a religious place but that was not the case “...I think that was a detrimental aspect...it was really important that people realized...palliative care was open to everybody” (Roth, 2010)⁴⁶. Some people may

have been deterred from accessing services because of assumptions and misunderstandings about religious requirements (Roth, 2010)⁴⁷. There were other cultural assumptions which impacted on bereavement services:

“...I...thought that it was important that we produced some...little pamphlet, which was more generic than Christian...I was going to defend everybody’s position...I needed to have the cross removed from the front of the pastoral care team’s...they were obviously feeling that a Christian symbol would be generally acceptable to everybody as a symbol of pastoral care...I didn’t think that it was...we needed to choose something...that...felt more inclusive” (Roth, 2010)⁴⁸.

Earlier assumptions about bereavement services needed to change to reflect a more encompassing kind of support in a modern time. One of the greatest difficulties for those providing oncology and cancer support was that there were so many different requirements. What was ‘right for one was not right for another’, therefore trying to provide a service that allowed individuals to pass through the system effectively, and in a dignified way was the greatest challenge (Youren, 2010)⁴⁹. Consequently, it was important to acknowledge that a range of perspectives existed when planning individualized care. It suggests that this was similar to the methodology underpinning my study because it had been important to capture differing accounts in order to reveal a broad story (Thompson, 1988). The participants learned about individual needs in the course of time, and this enabled them to personalize care (see chapter 5). Hockey (1977) argued that the nurse’s contribution to care ‘...in the context of change is her care of the person, rather than the treatment of a condition’ (Hockey, 1977, p.148). Next I explore how other obstacles were dealt with and consider how this impacted on the development of *tripartite* services.

6.5 Conquering obstacles

There were six key qualities identified as being important in overcoming the challenges: charisma and social connections, facilitating patient led support, opening up difficult conversations, negotiating struggles, dealing with stigma and managing through examples. I will examine each one here:

Charisma and social connections

Individual charismatic qualities were used to generate support:

“...when I started working with Malcolm, I WENT everywhere and MET everybody...I made sure they knew me... You can't beat personal...face to face contact...that's essential, if you've got an idea...you've gotta go out and share it with other people” (Youren, 2010)⁵⁰.

The ability to network provided an opportunity to use persuasive social powers to generate enthusiasm and ultimately get new concepts approved (James and Field, 1992). Charisma also played a significant role in overcoming barriers, for example, in relation to the drop-ins:

“Malcolm asked me did I know any people...who'd I'd met and I said Glyn...Glyn and his wife were...one of the very first...who came to the drop-in and they knew other people” (Roth, 2010)⁵¹.

There was a drive to bring people together who already knew each other; the network grew in time because those within it were able to attract new interest. Many participants were able to take advantage of serendipitous encounters in a strategic way, which brought more people on board. For example, in 1983 whilst visiting friends, Lizzie Watson (a masseuse – see chapter 4) was introduced to Pippa Youren. Following a discussion about cancer support services ‘...Pippa was full of enthusiasm suggesting that maybe massage could be helpful in relieving stress and anxiety...’ (Watson, 1996, p.1)⁵². Pippa Youren soon introduced Lizzie Watson to Malcolm McIlmurray, and she became the first massage therapist for the cancer support services (Watson, 1996)⁵³. These kinds of charismatic and social factors were common, and they brought a labyrinth of people together to shape the services. Similarly, many of the individuals interviewed by Clark et al (2005) were also charismatic and were able to use this quality to assist them as they developed hospices. Tansey and Overy (2012) also observed that charisma was an important asset because it

was used to persuade influential characters to support the development of palliative medicine.

Facilitating patient led support

The accounts suggest that these services were not for everyone, many were “too proud” to ask for help so they did not access the support groups (Youren, 2010)⁵⁴. Others were suspicious because before the services began massage was seen as being contra-indicated for those with cancer. Therefore, when it became available ‘...people were quite reluctant to take up the offer...’ (Watson, 1996, p.2)⁵⁵. Furthermore, it was particularly difficult to get men to accept therapy (Youren, 1996)⁵⁶. One way round this was to encourage people who had found it useful to persuade others to have a go (McCaldin, 2010)⁵⁷. This peer group encouragement suggests that in addition to charisma, cultural factors also impacted to shape how these services were provided.

Opening up difficult conversations

Struggles arose when proponents attempted to understand more about end of life issues at the hospice. By way of illustration, although participants said there was a need to open up the debate on cancer/palliative care, some people simply did not want to confront the issues. Many of those involved in local hospice care were keen to have a more open approach and tried to be creative about this. Hockey (1977) argued that it was precisely in the care of the dying that nursing as an art could come into its own because for many of the patients medicine had little to offer. One such artistic approach in Lancaster was the ‘sculptors in residence’ project, which did succeed in getting people talking but it also created controversy (Corkill, 2010)⁵⁸:

“...figures...were...stick figures...cancer patients often go very...thin...this brought up a lot of...painful feelings...more relatives...than patients great thing about Aine was that she would talk to people...so...having that diffused...people started talking about REAL feelings...turned out very beneficial it could have gone either way

if...Aine hadn't been there...it's no good stirring things up unless somebody is there to...talk it through...get to the bottom of this and Aine did...things were out in the open...controversy isn't always bad" (Youren, 2010)⁵⁹.

Some individuals were receptive to the sculptors and used the project to talk about experiences; others though found it too difficult. Therefore it was necessary to have someone to facilitate conversation on end of life issues if that was what individuals wanted, so once again we can see that having the 'right' staff was important to the development of these services.

Negotiating struggles

There were differing perspectives coming from within the cancer support organization, and these impacted on how complementary services developed:

"When I met her she was saying it is a bit odd because we have to be sort of smuggled in (laughter)...think I'd be the second one...so by the time I am there we were just about allowed to be named" (Ormerod, 2010)⁶⁰.

There was some wariness within the support group over the use of counselling when it was first introduced, this impacted on the services by increasing the pressure for high standards because therapy had to be 'credible' (Youren, 2010)⁶¹ (see chapter 5). In addition, there were some who worked less comfortably with the services:

"...people had an image of...social work...usually...negative...It was particularly difficult...the meeting in the hospice...didn't feel that I was very welcomed...I was determined...I was going...they were my clients...when I left...Dr. McIlmurray wrote an article...wryly commented on the fact that...we had a shaky relationship...because I carried on doing that job and...there were good

reports...eventually, he was the one that said ‘would you come and work here?’...and it came alright in the end...when I went to the hospice, the hospice was sold on the idea...apart from the trustees who didn’t know what social work did...” (Goad, 2010)⁶².

Initially, the community social worker experienced some challenges in gaining acceptance and this was because the role had a negative image. Through social negotiations the trustees were persuaded that a social worker would complement the multidisciplinary team and benefit palliative care. In the course of time the services changed for the better, from a social work perspective because by 1996 they included a hospice social worker.

Dealing with hospice stigma

There was some resistance to the hospice, and it is notable that St John’s provided free accommodation to the cancer support services between 1985 and 1989. The collaboration provided an opportunity to break down barriers by using charisma to persuade individuals to ‘step into the hospice’ for complementary therapy (McCaldin, no date):

“...there were people who didn’t want to walk up the hospice drive, didn’t want to be involved with a place that they saw as where people died...once...in you didn’t get out...We tried to persuade people...a hospice wasn’t anything like as frightening as they were...imagining...great advantage in being able to come in for a drop-in...see what it was like and know that they could go home...some people weren’t persuadable” (McCaldin, 2010)⁶³.

It was difficult to get some individuals to use complementary therapy when it was based at the hospice. Yet when the participants sanctioned change individuals were persuaded to use the hospice. This was likely to have been because of the influence of the protagonists on the perceived benefits of complementary therapy (as Nicolson and McLaughlin, 1988 highlighted in the debate about the aetiology of multiple sclerosis).

Managing through examples

The Cancer Support Nurses approached challenging situations by attempting to conjure up support for the way in which they worked (Maguire, 2010)⁶⁴. One way to gain acceptance from the doubtful and encourage them to work with the nurses was to demonstrate the benefit of the services ‘first hand’. In the wider context, Hockey also used positive experiences of nursing research to transform relations between district nurses and General Practitioners (Dopson, 1985). In a similar way, some of the Cancer Support Nurses used constructive experiences to gain respectability from those who had initially been sceptical about the facilities (McCann, 2010)⁶⁵. The Cancer Support Nurse had a very important position liaising between oncology and community services. Home visits were seen as a vital extension of the role ‘for they uncovered misunderstandings...fears...and unnecessary suffering’ (McIllmurray, Gorst and Holdcroft, 1986, p.670). Despite earlier strain in time the Cancer Support Nurses used positive examples of their approaches to ‘win over’ support:

“You use quite a lot of psychology...often try and word it in such a way that they thought it was their idea in the first place...Tentatively trying to make relationships ...I worked very hard trying to get them to accept it, and to accept me” (McCann, 2010)⁶⁶.

These illustrations suggest that it was important to collaborate in order to provide a comprehensive service and gain acceptance from a broader group, but this took time to achieve. In the course of time the increasingly specialized services brought different challenges and these are now examined.

6.6 Difficulties of specialization

An earlier dependency on the hospice, subsequent development of expertise, and later emergence of formalities were associated with difficulties that arose when the cancer and palliative care services became more specialized. I will discuss each in detail.

6.6.1 Dependency on the hospice

I have explained that the philosophy of the hospice was kind, compassionate and made people feel safe (see chapter 5). Some individuals were dependent on these services, but this became a problem when the hospice changed into a specialist palliative care unit about 10 years after opening:

“...there were a considerable number of patients who stayed...in specialist palliative care terms for an inappropriately long length of time when they could have been living their lives with the appropriate support at home...it may be that there wasn't as much support to be had at home...that was the change that needed to be brought about...we had a patient who stayed for that year...we undermine people's confidence to go back out into the world...made them...very dependent...it was a very difficult change to bring about because the hospice was built on the money...raised by local people...a lot...thought, 'When I'm getting near the end of my life I will go in there.'...when it came to questions of discharging...they were...shocked...they thought they could stay forever...the amount of patients you were reaching, was incredibly small, because you weren't discharging...there was a level on some people's parts, of outrage...We paid for this hospice...it was a very tricky transition...”(Roth, 2010)⁶⁷.

The way in which care was carried out was similar to 'total care' because it addressed physical, psychological, social, and spiritual aspects of illness (Saunders, 1965; Saunders 1984). Yet this kind of care was perhaps provided too early in the 'disease trajectory' for specialist palliative medicine. When changes were made they created an amount of strain because they disrupted different viewpoints from an earlier era. The key reason being that the hospice was as Sister Aine had said built “By the people for the people” (Warren, 2010)⁶⁸. Correspondingly, there was a sense of ownership and expectation that in return for raising funds there was a reciprocal right to use it. There was a need to educate people about alternatives such as hospice at home support, as they might not have been familiar with that approach. However, such support was not available at the time as these services

predate hospice outreach facilities (see chapter 4). One reason for lengthy admissions initially was due to wider social circumstances:

“...people stayed in much longer...particularly people who were widowed or single. Rather than being given a lot of home help...and it was very successful” (McCaldin, 2010)⁶⁹.

The accounts suggest that the lengthier admissions in the early days were beneficial if individuals lived alone and lacked home support. Yet longer periods of admission meant the numbers accessing the hospice were relatively small, and those who were admitted did not live the end of their life with their families. This became more problematic in the mid 1990s when greater changes were necessary in order for the hospice to receive recognition as a specialist palliative care unit:

“...we were running a, I mean, this would be to demean it because, like an excellent nursing home...in the sense that not so many people were being discharged. But we needed to...be able to prove our case as a specialist palliative care unit” (Roth, 2010)⁷⁰.

The historical reliance on hospice services made it difficult later when there was a need to reflect policy requirements in order to gain respectability as a specialist unit. By this time, the purpose of the hospice was changing. Instead of it being a place where people went at any stage for respite as well as at the end of their lives, it moved towards becoming a specialist palliative medicine unit. Consequently, it was necessary to promote more independence and increase discharges. Therefore admission criteria were introduced, which meant that the focus was now on admitting those with specialist palliative care needs that required the expertise of a specialist in palliative medicine (see chapters 4 and 5).

6.6.2 Expertise and formalities

Here we see that as the function of the hospice shifted so too did the philosophy of care in order to accommodate it, and six main factors were associated with increasing tension. First, the early approaches that were used to provide hospice and palliative care were not appropriate for specialist palliative care:

“CancerCare...I had a certain amount of strain with them because people coming into the hospice...have to come in for specialist palliative care...CancerCare found me a bit of an irritant because I was wanting to get the hospice right...very different hospice...to what I was used to...it was...under the oncologists whereas palliative medicine was already becoming a speciality in its own right...it became quite a hard time...people coming a few times a week...a number...did not have cancer. They...just came forever...on the wards, there were people who did not need to be there...They were not needing specialist palliative care...would come in because they needed a week’s break...expenditure went through the roof...Once you got a very sick population having blood transfusions, the nurses practically revolted when I said we are going to do blood transfusions...I found this stressful...we had to be credible” (Ellam, 2010)⁷¹.

These later challenges arose because in the early days the hospice provided respite and social care to individuals with cancer, multiple sclerosis and other chronic conditions as well as psychological and spiritual support from diagnosis to the end of life (The North Lancashire and Lakeland Continuing Care Trust, no date). This approach was not considered appropriate when the hospice changed into a specialist palliative care unit because the consensus then determined that only those with specialist palliative medical problems could be admitted. Higginson (2005) found that these included complex physical, psychological, social and/or spiritual problems; for example pain, breathlessness, anorexia, bowel problems, anxiety and/or difficult family situations that could not be met by the caring team. Doyle (2005) argues that one reason for the challenges is because the ‘hard’ side of palliative care, which is focused on the management of physical symptoms, is in tension with the ‘soft’ side (psychosocial and spiritual issues). For Doyle it is the ‘balance’ between them that constitutes the holistic nature of palliative medicine (see chapter 1).

Second, there were wider ramifications when facilities became more structured as attempts were also made to separate the *tripartite* services. The hospice had operated closely with oncology and the cancer support services, but by 1994 in order to gain respectability from other doctors in the field the hospice had to become a specialist palliative medicine unit. It needed to be independent so that it could focus on providing expertise to those who required it. Therefore it was no longer closely connected to the cancer support services or oncology. This made it difficult for those that did not require specialist treatment but had previously accessed the hospice:

“...they started to be a bit fussy...over who was admitted and so a lot of the...nursing home type patients started to not to be allowed to come...which some people didn't like” (Corkill, 2010)⁷².

Third, in the course of time there was concern that the hospice could become over medicalized:

“...there was a feeling that we shouldn't over-medicalize, this, in some places had gone too far. The medicalization of terminal palliative care, end of life care, it's become another discipline like all the others across the road at the Infirmary. We need to guard against that. The medical arm of specialist palliative care...has got to recognize that...doctors may not be the top dogs in this. They may be very important but they may be that bit over there rather than the bit in the middle” (Warren, 2010)⁷³.

There were tensions over concerns that potentially the hospice could become medicalized, and these sentiments also came from the wider echelons of specialist palliative medicine. Kearney (1992) argued that in the drive for credibility services were becoming like other branches of specialized medicine, where the focus was on physical symptoms at the expense of psychosocial ones (see chapter 1). Yet the pioneers of the modern hospice movement initiated developments that were a compassionate response to needs that were

not being met by the medical model. Fourth, as palliative care became more specialized the autonomy of the Cancer Support Nurse was diminished which also added to the strain:

“I had difficulties...with...nurses who have the authority to put anybody into hospice whenever they wanted...I wanted to keep the GP as the key person...Macmillan nurses saying to me ‘...I have arranged for...to come in tomorrow.’ I would say, ‘...why is she coming? What is her medical problem’...I insisted that nobody was to come without the GP either ringing me or sending a letter...deeply unpopular...” (Ellam, 2010)⁷⁴.

The change created difficulties for the nurses who had previously experienced extensive levels of authority:

“...it became...much more for symptom control...less for respite...that was a pity...respite care was a very valid reason for getting people in...after Margaret Ellam left it became a battle...admission meetings every day...I hated this...we were on the front line...you could see...what was important to people...it was so lovely to be able to say, ‘I’ll let you know today’ ‘cause it was today that they were on their knees...they would read a form and say ‘Oh, there wasn’t a good enough reason to come in’...I’d lose credibility...” (McCann, 2010)⁷⁵.

As the criteria for admission became more structured the power to make decisions about who was admitted was limited to doctors. Yet initially the Cancer Support Nurses arranged admissions for respite because they saw people in their own home and felt best placed to decide what they needed. Respite was crucial to avoid a crisis and preventing nurses from admitting undermined trust. Fifth, specialist palliative medical problems were now seen as the only ‘real’ problems (Nicolson and McLaughlin, 1988 found that individuals understood the aetiology and problems of multiple sclerosis from the perspective of their specialism - see chapter 2). Therefore they took precedence over needs that did not require input from a specialist doctor. Similarly some volunteers found the formalization of day care admissions created tension because the criteria were more stringent, and the length of

time individuals could use the facilities was restricted. People were told that they could access day care for a specified number of sessions, but at an earlier time they had used them for as long as they wanted (Carne, 2010)⁷⁶. Sixth, as the hospice became increasingly more specialized there was also a need to provide palliative care education which created some strain:

“...it was not fair or...feasible, to ask nurses to come in their own time to have education...that involved...altering completely the shift patterns...Extremely difficult...some...didn't see the necessity...and thought people should just get on with the job...I was...saying to...nurses...‘you now need to go and...get a specialist qualification’...Some...would say, ‘...I've been doing this job for...I don't need to do this’ and I would say...‘you will be supported...we will be obliged...If we're going to offer our services...as a specialist palliative unit’...” (Roth, 2010)⁷⁷.

Education was a key factor in making the hospice ‘acceptable’ from a specialist palliative medicine perspective (Clark et al., 2005; Overy and Tansey, 2012; Small, 2000). The shift patterns had to be changed to facilitate this because there was no time in the earlier 12 hour shifts to provide specialist education. Shortening the shifts enabled training to take place during the working day when there was an overlap of staff to accommodate it. This change signified the value placed on education and was welcomed by participants. Nevertheless, some staff did not embrace the need for education when they ‘had been doing the job for a long time’ (Roth, 2010)⁷⁸. These agitations were addressed by persuading staff to specialize in return for a higher grading status with more pay (Roth, 2010)⁷⁹.

There were also social, historical, political and professional mechanisms operating in the wider context to shape these services. For example, policy was eventually introduced as a result of earlier findings emanating from work like the Report of the Working Group on Terminal Care (1980). There was also the circular issued in 1987 by the Department of Health that required Health Authorities to examine their arrangements for terminal care (Higginson, 1993). Palliative medicine was granted subspecialty status in 1987 and that assured its credibility as it was now formally recognized as a specialist area in its own field

(Royal College of Physicians, no date). All of these broader factors impacted to change the hospice into a specialist palliative medicine unit with more policy, structure and professional appointments. These changes were similar to the second stage of the EPOR (Pinch and Bijker, 1984). For example, accounts suggest interpretative flexibility disappeared because consensus emerged to say what kind of specialist palliative medicine services were acceptable. The third stage of the EPOR linked these closure mechanisms to the wider social, professional and political milieu I have described because practice and policy were shaped by these external factors. Similarly, professional bodies were created to represent the interests of those working in the field of oncology. When the Royal College of Physicians recognized medical oncology as a specialty in 1985 this brought credibility to the field (Association of Cancer Physicians, 2012; McIllmurray, 1987). Furthermore, these professional and political mechanisms also shaped the development of local cancer services. For example, the Association of Cancer Physicians commissioned a working group at the end of 1985 to make proposals for the development of cancer medicine in District General Hospitals (McIllmurray, 1987) (see chapter 1). This policy made it feasible for medical oncology to develop locally in a district setting. Moreover, there was a long term national plan for cancer and palliative care services (Department of Health, 1995). In the next section I will explore the struggles that arose in relation to appraising the cancer and palliative care services.

6.7 Appraising care

Some accounts revealed that there were challenges relating to ‘measuring’ the impact of the cancer and palliative care services. Two key issues were noted as to possible explanations for this. First, the difficulties appeared to be linked to tensions between quantitative and qualitative evidence based approaches. For example, when the cancer support services received some funding from the National Health Service they were expected to reciprocate by providing statistics about the impact of complementary therapy:

“...our grant...required us providing statistical information...fighting keeping the anonymity by saying, ‘okay we’ll tell you where they live but we don’t want to give any details...you can have them as numbers, where they live and age ranges’ (McCaldin, 2010)⁸⁰.

There were concerns about the level of ‘interference and control’ the funder might exert over services as they struggled to maintain independence (McCaldin, 2010)⁸¹. There was some tension in the relationship between the local charity and the larger, official organization. These challenges could have been due to different organizations assessing the impact of care from contrasting perspectives. The Health Service was more structured and tended to look at quantitative measures/cures because it was familiar with these interpretations; the cancer support services relied initially on anecdotal and then qualitative evidence. Several participants commented on how difficult it was for them to ‘prove’ what they were doing was making a difference:

“...we needed to prove all sorts of things...one of the difficulties about proving your case when it comes to health visiting of any sort, is that you are trying to show that without intervention, such and such might have happened” (Youren, 2010)⁸².

It was difficult to persuade sceptics to ‘see’ the benefit of complementary therapy in cancer and palliative care work (McCaldin, 2010)⁸³. Particularly as qualitative forms of research were not valued as much as conventional approaches (Hockey, 1982a; Hockey, 1982b). The accounts reflected experiences of conventional perspectives, and this suggests they were rational or linear in their approach to the production of evidence (Abraham, 1994; Alderson, 1998; Sackett et al., 1996) (see chapter 2).

Second, the proponents did not have a comparable evidence-base to that of conventional medicine. Where there are competing forms of knowledge Nicolson and McLaughlin (1988) found in work on multiple sclerosis that the burden of proof is heaviest on the weaker group, here that rested on those providing the cancer and palliative care facilities. When these services began anecdotes suggested that individuals derived great benefit from supportive holistic therapy. One challenge for the proponents was how to make sense of these experiences in order to explain the value of supportive services/therapies. The pilot study undertaken in 1981 (see chapter 4) was also conducted to ‘...monitor progress of patients undergoing chemotherapy and facilitate the continuing care of chronically and terminally ill...’ (Holdcroft, 1984, p.103). It was difficult to ‘quantify’ the effectiveness of the work but the staff said they appreciated ‘...the additional knowledge about the patient

and the family' (Holdcroft, 1984, p.104) provided by the Cancer Support Nurse. Families also benefited because they were relieved to have access to a Cancer Support Nurse, who remained constant and with whom they could communicate on their own level.

McIllmurray, Gorst and Holdcroft (1986) formed a view that failure of the medical profession to recognize the need for emotional support and lack of a national policy could explain why individuals sought out independent centres such as Bristol and Morecambe Bay. The researchers stated 'Unfortunately, these centres engage in curious treatment strategies for which there seems to be no scientific justification, but we have much to learn from their compassionate approach and the forms of psychological support they offer' (McIllmurray, Gorst and Holdcroft, 1986, p. 670). McIllmurray, Gorst and Holdcroft (1986) advocated that care should be a comprehensive, continuous process of the physical/psychological consequences of illness, and should follow individuals through to the terminal stage. Despite difficulties in quantifying the impact of services several encouraging signs were reported such as rising attendances at support meetings, fully booked relaxation sessions and more families accessing counselling facilities. There was a strong feeling that overall morale had '...improved considerably' (McIllmurray, Gorst and Holdcroft, 1986, p.671).

Further research in the form of a descriptive study was carried out in the local area to illustrate the demand for supportive care (McIllmurray and Holdcroft, 1993). Between 1990 and 1991 513 patients, 243 relatives and 143 bereaved were referred to five Cancer Support Nurses. Cancer support services at that time consisted of patients' and relatives' meetings, drop-ins, a swimming group, social day care, creative art groups and relaxation therapy. The latter therapy included massage, hypnotherapy, breathing methods and the Alexander technique. There were 32%, 12% and 34% respectively that used complementary therapy. The researchers argued that the high demand for supportive care/relaxation therapy '...suggests that services should be made available in any district health provider unit' (McIllmurray and Holdcroft 1993, p.861). The study was important because it looked at the use of complementary therapy as a response to meeting emotional needs, and it came at a time when most interest was focused on specific cancers and chemotherapy/radiotherapy treatment (Payne, 2011).

On a critical point, another reason for the high uptake of complementary therapy could have been because the Cancer Support Nurse had access to many individuals and could assess their suitability for the services. Continuity of care meant the nurse could reassess and remind people of the support available particularly during times of increased anxiety, chemotherapy, relapse or when treatment was withdrawn. These factors might have impacted on decisions to use therapy. Yet the researchers did take steps to prevent coercion by considering whether individuals had sufficient information to make an informed choice. No formal evaluation of therapies was made but ‘...detailed records...’ were ‘...kept and a...note...made of the reason for clients ending treatment’ (McIllmurray and Holdcroft, 1993, p.862). These notes were used to estimate the proportion of clients that had benefited from each of the four types of therapy. The research would have been even more engaging if it had included interviews to find out about the experiences of those accessing services. It could have revealed why people took up the facilities offered and the impressions formed. Of course this would have taken time and incurred costs which would have been an added challenge as therapy was provided free to users through charitable donations, and the supportive work was done in participants ‘own time’. Nonetheless, the research was extraordinary in gathering some evidence of the demand for complementary therapy; it concluded that there was a substantial demand for services. It recommended supportive care should be an integral part of any cancer service to address emotional needs, and it raised the question as to why it was found so rarely in other places (Addington-Hall et al., 1993). One problem was that specialist services in district hospitals were usually provided by visiting radiotherapists, and it was difficult to develop continuous supportive care when they were based miles away. Often there was no local consultant who took responsibility for coordinating services; Clinical Support Nurses, where they existed were working in isolation or restricted to providing terminal care.

During 1997-2000 another local study looked at the ‘significant unmet psychological needs’ (a need deemed important by the carer or patient which had not been met) of patients and their main carers by the cancer services (Soothill et al., 2001a; Soothill et al., 2001b). The study about patients used questionnaires, the one involving carers used questionnaires and a smaller number of follow up interviews. Both patients and carers expressed the importance of good relationships with health professionals, and the need for honest information. Few expressed dissatisfaction with these suggesting that cancer services were often successful in providing sensitive care and good information. However,

other aspects of illness caused difficulty. The significant unmet needs of carers related to aspects of managing daily life. Those without a car found public transport expensive, inconvenient and a few said it was threatening. There were emotional difficulties involving feelings of guilt, helplessness and unpredictability about the future. Social identity was also an unmet need and the value of working was raised as a means of enabling the carer to maintain a separate identity. These were the same areas of significant unmet needs that concerned patients however carers had more of these, which reflected their comparative neglect (Soothill et al., 2001b).

The carers that had unmet needs were more likely to be those who were not the patient's spouse or partner, or had other caring responsibilities. They were less likely to have friends/family to help and were also in poor health, or the patient had reached the palliation stage. In the patient group those who were younger, had longstanding illness or disability, did not own/have use of a car or had no religious faith were more likely to experience significant unmet psychological needs. From a critical viewpoint carers were recruited via initial contact with patients. A questionnaire pack with patient and carer questionnaires was sent to the patients. This approach could have inhibited carers from responding as openly as they might have done, as they knew that the patient was aware they had been asked to complete a questionnaire. There was a chance the patient might read their answers, therefore carers could have played down their level of unmet needs for fear of upsetting them. Other participants were referred by consultants and their staff; they might have unintentionally referred those who appeared to be coping well, or not as the case might have been. The researchers acknowledged there was some bias as clinicians filtered out those whom they felt were too unwell or distressed. Persons with breast, colorectal, lymphoma or lung cancers were approached but those with other types of malignancies were excluded, and they might have had contrasting experiences. Furthermore, questionnaires did not provide any context and their predefined questions restricted individuals to the answer choices, which might not have fitted their situation. Any unanswered question was assumed to have been unimportant and therefore not an unmet need. However, it is conceivable that it was significant but the carer did not answer as they did not want to worry the patient. These illustrations show that there were many struggles in relation to appraising the cancer support services, yet in the course of time local studies began to emerge which started to address these challenges.

6.8 Summary

This chapter has reported on the struggles that arose as cancer and palliative care services developed in Lancaster. It has explored how charismatic individuals addressed tensions and influenced the development of *tripartite* services. The study's methodology was embedded in oral history accounts and revealed that participants challenged prevailing rationalities and searched for different ways to practice and create policy (Fingerroos and Haanpaa, 2012; Mallinson et al., 2003). The protagonists were willing to take emotional and psychological care needs seriously and risked being discredited for not conforming to convention (Soothill and Thomas, 1998). The work by Soothill and Thomas (1998) did not reveal the tension that my study uncovered. Although the researchers commented at the time that they wondered whether there might be others who would have a different tale to tell. My study has uncovered some of the struggles to furnish the void in our evidence base, and this is one of its key contributions to new knowledge (see chapter 7 for discussion of key findings and how my study adds to the work of Soothill and Thomas, 1998). Those involved in setting up the facilities said they did not need to change existing services and that made the job 'easier' (Youren, 2010⁸⁴; McIlmurray, 2010⁸⁵). Yet this chapter has shown that it was not straightforward, a huge amount of creativity, persuasive skills and sheer hard work were essential prerequisites.

The oral history accounts suggest there were individual, social and historical factors that impacted to shape the development of *tripartite* services. Furthermore, in the early days the lack of strategy and professional representation meant that services were incredibly flexible, like the first stage of the EPOR when interpretative flexibility is displayed (Pinch and Bijker, 1984). However, this also made it challenging for those trying to develop these services because they had to justify themselves in order to make local policy. The key reason for this was that they were in the marginal group, there was no special cancer or palliative care professional body to represent them, or influence others in the professional community. They were in a similar position to those in the weaker group in the debate on the aetiology of multiple sclerosis (Nicolson and McLaughlin, 1988). Therefore they lacked protection, power and respectability of those in traditional fields and this created tension in the early days.

In the course of time the wider social, historical, political and professional mechanisms that I have discussed operated in the broader context to shape the local services. I explained that by 1995 there was a long term plan; this policy advocated more of a patient centred approach taking into account families and carers' views, yet many at the grass roots of cancer and hospice work (including the local services) had practised like that for many years (Department of Health, 1995; Saunders, 1996).

This chapter answered research questions about how participants came to be involved in local services via social networks, the philosophy of care, change, links forged/broken, paths not taken, charisma, routinization, research, education and challenges. It also addressed the first aim of the study - 'to ascertain how individuals developed cancer and palliative care services in one community', the third aim - 'to place the research findings about service development in the wider context of cancer and palliative care issues' and the fourth aim - 'to increase understandings about the development of cancer and end of life provision over time'. Overall the chapter has contributed to furthering our knowledge about the ongoing picture of how local *tripartite* services developed. Therefore it adds to the findings in chapters 4 and 5 and assists in answering the overarching research question. I will now move on to the final chapter which brings together the key findings and conclusions of the study.

¹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

² Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.

³ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

⁴ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.

⁵ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.

⁶ Shelley, C. (2010). Interview with Sara Denver in Lancaster on 4 October.

⁷ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.

⁸ McKinney, H. (2010). Interview with Sara Denver in Morecambe on 27 September.

⁹ McCaldin, M. (2010). Interview with Sara Denver in Stocksfield on 9 September.

¹⁰ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

¹¹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

¹² Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

¹³ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.

¹⁴ Youren, P. (1996). A History of CancerCare North Lancashire and South Lakeland. July.

¹⁵ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellet on 25 May.

¹⁶ McIlmurray, M. (2010). Interview with Sara Denver in Over Kellet on 25 May.

¹⁷ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.

¹⁸ Williams, T. (2010). Interview with Sara Denver in Hest Bank on 11 May.

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- ¹⁹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ²⁰ Lomax, R. (2010). Interview with Sara Denver in Lancaster on 22 April.
- ²¹ McCann, C. (2010). Interview with Sara Denver in Grange Over Sands on 5 October.
- ²² McCann, C. (2010). Interview with Sara Denver in Grange Over Sands on 5 October.
- ²³ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.
- ²⁴ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ²⁵ McCaldin, M. (2010). Interview with Sara Denver in Stocksfield on 9 September.
- ²⁶ Fall, J. (2010). Interview with Sara Denver in Lancaster on 9 November.
- ²⁷ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ²⁸ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ²⁹ Howarth, J. (2010). Interview with Sara Denver in Lancaster on 9 November.
- ³⁰ Hearn, P. (2010). Interview with Sara Denver in Lancaster on 15 October.
- ³¹ Hopkins, D. (2010). Interview with Sara Denver in Lancaster on 23 November.
- ³² McIlmurray, G. (2010). Interview with Sara Denver in Over Kellett on 11 October.
- ³³ Warren, J. (2010). Interview with Sara Denver in Milnthorpe on 14 September.
- ³⁴ Hunt, J. (2010). Interview with Sara Denver in Kelleth on 19 October.
- ³⁵ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.
- ³⁶ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ³⁷ Warren, M. (2010). Interview with Sara Denver in Lancaster on 12 July.
- ³⁸ Maguire, E. (2010). Interview with Sara Denver in Arnside on 9 July.
- ³⁹ Parker, L. (No date). *A History of St John's Hospice Lancaster 1976 to 1986*.
- ⁴⁰ Warren, M. (2010). Interview with Sara Denver in Lancaster on 1 July.
- ⁴¹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ⁴² McCaldin, M. (2010). Interview with Sara Denver in Stocksfield on 9 September.
- ⁴³ Fall, J. (2010). Interview with Sara Denver in Lancaster on 9 November.
- ⁴⁴ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁵ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁶ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁷ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁸ Roth, S. (2010). Interview with Sara Denver in Whittington on 22 July.
- ⁴⁹ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
- ⁵⁰ Youren, P. (2010). Interview with Sara Denver in Hest Bank on 5 July.
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Chapter 7

DISCUSSION AND CONCLUSION

7.1 Introduction

This oral history and documentary reconstruction was focused on addressing the overarching research question - 'how were cancer and palliative care services developed in Lancaster 1976-2000?' This final chapter brings together the main findings from the study and presents conclusions, highlighting the key contribution to knowledge. It confirms the extent to which the aims of the study were achieved by drawing on the outcomes of earlier chapters. Furthermore, it explains how I have added to the field by mentioning links with and distinctions from the literature. This chapter also highlights the gaps that have been revealed for further study and recognizes the limitations of the research. A number of reflections are made as to what worked well and what did not during the study. Finally, some comments are also provided which conclude this chapter and the thesis.

7.2 Research aims achieved

In the first chapter I reviewed the literature and presented a bird's-eye view of the state of cancer and palliative care services between 1976 and 2000. Chapter 2 examined methodology and explained how it complemented the oral history method described in chapter 3. In chapter 4 I explored how the cancer and palliative care services started from 'scratch' and became 'routine'. Chapter 5 analysed the philosophy of care/practice, and chapter 6 investigated the struggles that arose in the course of time. In short, the key findings from these chapters informed us that very little research had been done which looked at how cancer and palliative care facilities evolve in the local setting. It was remarkable to find that cancer and palliative care services developed in the absence of long term national planning. Yet in the locality I studied amenities were comprehensive and care was compassionate, although there was tension at times. Furthermore, services were shaped by individual factors as well as broader social, historical, political, economic and professional mechanisms. All of these chapters taken together addressed the aims of this study which were:

1. To ascertain how individuals developed cancer and palliative care services in one community.
2. To capture experiences of how care was provided at the end of life.
3. To place the research findings about service development in the wider context of cancer and palliative care issues.
4. To increase understandings about the development of cancer and end of life care provision over time.

The extent to which the research aims were addressed is discussed here; I will look at each one in turn (see Introduction):

Aim 1: To ascertain how individuals developed cancer and palliative care services in one community

There are six key points in this section: To begin with this is one of the first studies that revealed how cancer *and* palliative care services (together) developed in the local setting. Second I argue that the data showed the importance of leadership and charisma to the development of services, third there was no long term national plan in place for the evolution of these facilities. Fourth the flexibility of those involved created malleable services, fifth emotional problems were perceived to be as ‘real’ as physical ones, and this was a significant director in the development of cancer support facilities. Sixth, there was tension at times in the early days and as amenities advanced. I will now discuss each element in detail.

In relation to the first point, overall this study uncovered the fine grained detail of how cancer *and* palliative care services developed in one place, in doing so it addressed the initial aim of my study and is one of the first local histories of this development. There was little by way of ‘local’ studies with which to compare the findings, but my work related to some aspects of that undertaken by Clark et al (2005). Furthermore, both studies used oral history and explored the development of hospice and palliative care. Clark et al (2005) did not examine local *tripartite* services in detail - that was not the study’s intention; it was concerned with the macro level of hospice developments nationally (see chapter 1). My study was broader in the sense that it explored the developments of cancer *and* palliative care services, yet in another

respect it was more finely tapered because it focused on the 'local scene'. At the Witness Seminar on the History of Palliative Medicine Kenneth Calman emphasised that it was very important to increase understandings about the contribution local hospices have made to their communities. It was suggested that in future it would be useful to have an oral history concerning how local palliative care services developed (Overy and Tansey, 2012). My study has gone some way to fill this void, although there were limitations because it was 'time' specific (see discussion on limitations later in this chapter).

Second, the oral histories have shown how important individual leadership, charisma and social networks were to the development of services in Lancaster (Thompson, 1988) (see chapters 1, 4, 5 and 6). These mechanisms in turn impacted to shape local services because they made progress possible. Exceptional individuals can act as a catalyst for social change because of the impact of personality in bringing about such transformation, but as an explanation on its own it is insufficient (James and Field, 1992 citing Weber, 1966). The data in my study revealed that charismatic individuals operated in social networks, which facilitated collaboration, ensured ideas were accepted and encouraged others to become involved. Analogous findings were reflected in the work of Clark et al (2005). Small (2003) also highlighted the importance of social connections on palliative care developments because it was during 'social networks' that most decisions were actually made. In addition, similar findings on the importance of these individual and social mechanisms and their impact on the development of hospices was uncovered by Overy and Tansey (2012). The ability of the method to uncover these broader links was a key positive feature, because it also revealed how many of the participants came to be involved in the organizations in the first instance (Mallinson et al., 2003). All of these findings went some way to answering questions about charisma (see chapter 3.6 question (j), and chapters 1, 4, 5 and 6) and how individuals came to be involved in the cancer and palliative care services (see chapter 3.6 question (d) and chapter 4).

Third, one of the most notable issues that came to light was that cancer and palliative care services emerged when there was no national strategy and development was almost entirely local, people were to a certain extent 'making it up' as they went along. There were concerns that facilities in the broader arena were fragmented, unevenly distributed and therefore

unequally available. They had grown up in an *ad hoc*, haphazard way with little long term planning or thought about the populations which they served (McIllmurray, 1992a; Report of the Working Group on Terminal Care, 1980; Sikora, 1992) (see chapter 1). This thesis has shown that services in the place I studied developed in a *tripartite* way, therefore they were comprehensive in the sense that cancer support and palliative care emerged alongside oncology services. This finding was helpful in addressing questions about philosophy of care (see 3.6 question (e)).

Fourth, the methodology and method complemented each other to reveal that at the macro level of local developments participants worked in a very flexible way, and the services that developed were also malleable. This flexibility appeared similar to the first stage of the EPOR and SCOT, when interpretative flexibility of scientific findings and technological artefacts is displayed in the early days of their creation (Pinch and Bijker, 1984), (see chapter 2). It suggests that in the beginning the participants were very autonomous as they determined consensus over what was considered an acceptable service. Creation of this local policy impacted to shape the way in which the cancer and palliative care services developed, out of few tangible assets and many intangible ones. There was a shared dream to find a better way of caring, participants worked hard and they felt part of 'something special'. Yet the devotion some gave in their own time also created challenges. For example, hospice staff worked for a year without a paid holiday, and there was no pension in the early days. Other participants found fund raising difficult at times because much of it had to be done in their 'own time', and it interfered with family life (see chapter 6). Participants were involved in several of the organizations which created connections between them, the services also collaborated and this coupling facilitated the *tripartite* arrangement. These findings went some way to addressing the question in relation to how participants felt about being involved (see chapter 3.6 question (f) and chapter 4). In addition they addressed questions about links that were forged between organizations (see chapter 3.6 question (h) and chapters 4, 5 and 6). Clark et al (2005) and Overy and Tansey (2012) also found there was a shared dream to do things better, a sense of being part of something special and a similar work ethic amongst those involved in developing hospice care at the macro level. Soothill and Thomas (1998) revealed similar findings about the development of cancer services in Lancaster.

Fifth, the pioneers disrupted the rationality of conventional approaches and searched for others ways to provide care (Pinch and Bijker, 1984). Emotional problems were perceived to be just as ‘real’ as physical ones, and this was a key driver for the development of the service (McIllmurray, Gorst and Holdcroft, 1986; McIllmurray and Holdcroft, 1993). Cancer support services evolved as a response to emotional and psychosocial problems, and complementary therapy was able to flourish in the cancer and palliative care settings. The work by Soothill and Thomas (1998) also highlighted that emotional and psychosocial needs were taken seriously (see chapters 1 and 6). The participants in my study went to some remarkable lengths to try to understand the experiences of those needing cancer and palliative care, one example was the use of sculptures to embody reflective end of life experiences. For others this created controversy, and the oral history provided a sense of the richness and diversity of individual perspectives (Thompson, 1988). Some of the volunteers thought the sculptures were too raw and would frighten patients, yet the artefacts were representations of patient’s experiences. This demonstrated the interpretative flexibility of a technological artefact in the SCOT. There was evidence of closure and stabilization in the second stage, when social pressure resulted in the sculptures (the problem for the volunteer group) being moved into a room and hidden from those who found them too raw (the solution). They were made available to those who wanted to see them in order to try and understand the bigger picture of death and dying in our society. The third stage of the SCOT linked these developments with wider social and economic mechanisms. For example, funding was obtained for the project to use the sculptures to get people talking about ‘real’ feelings, the public were more questioning which shaped developments and opened up the debate on cancer/palliative care issues. Pinch and Bijker (1984) argue that the factors/issues (here volunteers) that have the effect of closing the debate on controversy are usually not convincing to the ‘core set’. That appeared to have been the case here because Sister Aine ensured the statues were still available to those who wanted to see them.

The revelation of a *tripartite* service offering complementary therapy within an oncology and palliative care landscape suggests the local facilities were unusual (see chapter 4) (however, further work is needed – see below). In addition the services were also ‘comprehensive’ in the sense that hospice and supportive/emotional care was offered from the time of diagnosis to the terminal stage, which provided continuity of care. Furthermore, I found that prior to the

development of cancer and palliative care services avoidance tactics had been used elsewhere when caring for those with cancer or those who were dying, which was done to protect professionals (Clark et al., 2005; Mills, Davies and Macrae, 1994) (see chapter 6). Some of these historical experiences turned out to be the catalyst that led participants into this field of work. These findings contributed to answering question about philosophy of care and how participants became involved in the services (see 3.6 questions (e) and (d) (see also chapters 4-6).

Sixth, my study uncovered tension at the nascent stage of cancer and palliative care service developments and suggests this arose because of historical, social and professional mechanisms. For example, strategy and professional cancer/palliative care representation was lacking as described, but traditional medicine was also more influential than medical oncology, nursing, palliative care and complementary therapy. Within the conventional group the mind was focused on the mechanics of disease, and it privileged a linear approach to the generation of knowledge (see chapters 1, 2 and 6). However, those from the less powerful groups were the ones attempting to develop the cancer and palliative care services. Consequently, they had the greatest burden to prove themselves, their policies and moreover that emotional problems were as real as physical ones (Addington-Hall et al., 1993; Nicolson and McLaughlin, 1988). Nevertheless, similar social, historical and hierarchical mechanisms actually enabled the services to develop in the way that they did because they were supported by a doctor who was respected and influential. In addition, tensions in the wider context of oncology and general practice impacted to shape local cancer support services in such a way that they were constructed into complementary, rather than alternative therapies (Bagenal et al., 1990; Chilvers et al., 1990; Douglas, 1992). These findings answered questions about the challenges that arose (see chapter 3.6 question (m); chapters 4 and 6).

By revealing this history the research made a further contribution to knowledge because these struggles were not revealed in the earlier work of Soothill and Thomas (1998). My study found that similar 'ingredients' went into the 'recipe' for developing cancer support services. For example, people came together with a shared goal to improve care, they provided holistic rather than conventional care, emotional needs were taken seriously and the Cancer Support Nurses had more autonomy than nurses generally. Yet my study has taken our knowledge

further by uncovering some of the tensions that were not previously revealed. It ascertained how individuals developed cancer and palliative care services in one community and thereby addressed the first aim of the study.

Aim 2: To capture experiences of how care was provided at the end of life

The key aim of this section is to discuss how care was provided to individuals as they neared the end of their lives. I found that the methodology and method complemented each other to uncover developments at the micro level, and this helped to address the second aim of my study. For example, the research interpreted accounts to reveal the meaning of compassion and how compassionate care was provided to those nearing the end of their lives (see chapter 5). Furthermore, the oral history method was advantageous because it enabled participants to reflect on personal experiences of caring for individuals with cancer and those who were dying. I formed a view that this was because oral history was democratizing, and trust developed as the conversations evolved to reveal the most pertinent reflections. From a methodological perspective the accounts suggested that the philosophy of the protagonists resonated with some elements of social constructionism (Pinch and Bijker, 1984) (see chapter 2). In particular, the participants questioned conventional approaches, they looked for other forms of care to meet individual needs and went beyond the usual ways (there is some overlap with aim one above). Similarly, there was a shared understanding that a range of perspectives existed amongst those with cancer and palliative care needs, these sometimes differed to what the 'professional' thought a person wanted/needed, yet 'one way' was not necessarily better than another. In addition, there was a requirement to 'really listen' in the first instance in order to ascertain what somebody wanted (Saunders, 1996) (see chapters 1 and 5). Consequently, there were similarities between the philosophy relating to compassionate care, relativism and the doctrine of symmetry. The oral history indicated that an approach which focused on disease at the expense of emotional problems did not work in this field. People had differing needs depending on what constituted a problem for them. Moreover, there was a need to accept people for who, what and where they were in life which again resonated with a symmetrical approach because it was non-judgmental (Pinch and Bijker, 1984). Similarly, it complemented the theory of oral history because that also requires one to take a neutral stance (Thompson, 1988). The data here suggested that when a participant was able to do these things

there was an opportunity to ‘get alongside’ a person, ‘dance the tune they wanted to play’ and provide what was wanted and therefore needed. These were the key components of compassionate care, and the participants learned them in the course of developing the cancer and palliative care services (see chapter 5).

One limitation here was that since accounts are always partial, there might have been different experiences of care provision which were not revealed. Furthermore, in an interpretative study the finding produced may be one of many possible interpretations (Craggs and King, 2013; Murray, 2011). For example, some might interpret the philosophy underpinning compassionate care as being the ‘same’ as ‘total care’ practised by Saunders (1996) (see chapters 1 and 5), I interpreted that it was similar in a number of ways. For example, it resembled Saunders’ (1996) writings about her earlier practice which took account of psychosocial, spiritual and physical needs. A similar kind of holistic approach was reflected in the philosophy of care of the participants in my study. In addition, accepting people ‘...as themselves...’ (Saunders, 1965, p.5) was also important to those working at St Christopher’s Hospice (see chapter 5).

Yet my study suggests that it was also subtly different. The difference in what I found about compassionate care and total care was that compassionate care might be holistic, it might not – those practising it did not presume holistic care was what a person wanted. Rather, participants understood that a range of perspectives existed, what was ‘right’ for one was not necessarily appropriate for another. One reason for the subtle difference might have been because my work included the development of cancer as well as palliative care services, some participants were involved in several organizations and they brought a wide range of viewpoints to their work. For example, they used nature, crafts, sculpture and religion in a bespoke manner to reflect a person’s experiences, and as forms of therapy depending on what individuals wanted (see chapter 5).

These findings make a further contribution because they have increased our understanding on the meaning of compassion to those involved in developing *tripartite* services. In addition, the study revealed how participants provided ‘hands on’ compassionate care in the cancer care setting *and* hospice environment; little has been written on personal experiences of how

people have actually given compassionate care to individuals very near to the end of their lives. Firth-Cozens and Cornwell (2009) underscore that compassion ‘comes from the top’, and it includes honesty and may also require courage (see chapter 5). Cornwell and Goodrich (2011) observed it is not a ‘one size fits all approach’ because compassion can mean different things to various people, and the compassionate care giver never stereotypes but appreciates difference (see chapter 5). Kearney (no date) described soul pain and practices that created a feeling of safety and connectedness to the soul. In Kearney’s experience this connectedness brought wholeness and a sense of significance, which could help in the healing process at the end of life. Larkin (2011) advocates that it is important to interpret what compassion means in the context of death and dying, and how it underpins the approach to the care of dying people. He found that compassion occurs when an individual uses their heart to care for others (Larkin, 2011) (see chapter 5). Clark et al (2005) focused on how hospices developed in terms of structure, teamwork, bereavement care, spread and diversification, rather than individual accounts of how compassionate care was provided to a dying person in the local setting (see earlier chapters). My study was also similar to the work of Soothill and Thomas (1998) because it looked at the development of cancer support services in Lancaster during a similar period (see chapter 1). Yet it also went beyond that work because it included the development of local palliative care services and uncovered how compassionate care was provided there. Soothill and Thomas (1998) called for future research to explore the local development of services for care of the dying, therefore my study went some way to plugging this gap (see chapter 1). Overall my study uncovered the participant’s philosophy and captured experiences of how care was provided at the very end of life. It addressed the research questions on philosophy of care, spiritual care, complementary therapy and challenges (see 3.6 questions (e), (g) and (m)) and achieved the second aim of the study.

Aim 3: To place the research findings about service development in the wider context of cancer and palliative care issues

The oral history revealed a range of accounts about how the *tripartite* services developed. It complemented the methodology to show the links between accounts and the social relations in the wider context (Mallinson et al., 2003; Thompson, 1988) (see chapters 2 and 3). There were three key factors identified as to how broader mechanisms impacted to shape services. First,

social and economic structures influenced local developments because the Nuns were a workforce ready to staff the hospice. Therefore concerns about taking nurses away from the National Health Service hospitals to run a hospice were not revealed in my study (Overy and Tansey, 2012) (see chapter 1). In addition, the Health Authority transferred its contractual arrangements with St John of God Hospital to St John's Hospice, thus providing the finances to meet the 'running' costs.

Second, there were many links between the cancer support services and the hospice as they developed; several participants were involved in all of the organizations. They were also connected to one another socially, historically and professionally (there is some overlap here with the first aim of the study). This intimates that these mechanisms impacted on the shape of services because they brought individuals/organizations together, and this made them flexible and comprehensive. Similarly, CancerCare used the hospice premises for several years, this impacted on developments because it began to break down barriers to 'hospice', and people started to use cancer support services inside the hospice. Furthermore, some individuals used the hospice at early stages of illness as well as the final stages, which also made the services continuous and comprehensive. Moreover, these social and economic factors impacted in such a way to shape the hospice, so that it was not exclusively for people with cancer. Those with long-term medical conditions that had lived at St John of God Hospital were 're-housed' at the hospice. In addition, people with multiple sclerosis used the hospice for respite care because of social and economic connections to the Multiple Sclerosis Society. The national organization made a significant contribution towards the hospice project, and those working in the hospice reciprocated by providing respite care (see chapter 4).

Third, wider social, professional and political mechanisms operated to shape services. In 1985 a group of doctors interested in palliative care held a meeting in Birmingham and decided to form a professional association (Overy and Tansey, 2012). Malcolm McIllmurray attended the meeting and according to the delegate list there was only one oncologist present, which suggests that it was unusual for oncologists to be interested in developing palliative care resources. Similarly, the Association of Cancer Physicians took an interest in local services when they explored the future developments of district cancer services in England and Wales (Association of Cancer Physicians, 1994; McIllmurray, 1987) (see chapter 1). Moreover, there

were wider professional and political mechanisms operating to facilitate developments nationally. The Royal College of Physicians created the Association of Cancer Physicians and also recognized palliative medicine as a specialty. These are discussed below but my study suggests that they operated to shape local services because medical oncology developed at district level. Also within 10 years of opening the hospice changed into a specialist palliative care unit, and it became more structured because then it had to comply with national policy (Pinch and Bijker, 1984; Royal College of Physicians, no date) (see under fourth aim below for discussion). Furthermore, the absence of strategy initially also impacted to shape cancer and palliative care facilities generally because they did not develop in a *tripartite* way. Instead they were *ad hoc*, haphazard and lacked plans to bring them together in the National Health Service (Report of the Working Group on Terminal Care, 1980; Sikora, 1992) (see chapter 1). Therefore, the oral history and methodology enabled me to place the research findings about local service development in the wider context of cancer and palliative care issues, and this achieved the third aim of my study.

Aim 4: To increase understandings about the development of cancer and end of life care provision over time.

The fourth aim was the most challenging to achieve, and I think this was because the study was retrospective and longitudinal. Yet there have been calls for more of this type of work to increase understandings about palliative care needs and how these change over time (Grande et al., 2009). Nonetheless, one of the key findings related to change at the hospice when it became a specialist palliative care unit. Once more I found that the methodology and method complemented each other to reveal that at the macro level the service changed from being flexible, to one that was more structured with policies in place. Consensus had emerged to limit interpretative flexibility and map the shape of services. The process of stabilization completed the final construction to determine what was considered an ‘acceptable’ service (Pinch and Bijker, 1984). For example, the findings suggest that ‘professionalization’ (palliative medicine became a subspecialty of medicine), and the development of strategy impacted on the shape of services. Together they created more policy, structure and standardization (Higginson, 1993; Report of the Working Group on Terminal Care, 1980; Royal College of Physicians, no date). Yet these changes also created tension because the

philosophy of specialist palliative medicine collided with that of palliative care and social/respite care from an earlier time (see chapter 6). James and Field (1992) revealed similar findings in relation to routinization and professionalization of hospices (see chapters 1 and 4). Consequently, regulation increased accountability, drove up standards and made services more influential but 'standardized measures' stifled the creative, flexible, holistic and comprehensive approaches of an earlier time. Similarly, this kind of tension between local autonomy and top-down standard setting was recognised by Small (2003) as a challenge to the development of palliative care (see chapter 6).

The methodology and method were also complementary because rather than taking the end point of palliative care services (in accounts) as evidence of success, it was possible to link them with historical mechanisms to show (through a multi-directional model) the course taken was not the only one that could have been followed (Pinch and Bijker, 1984). For example, hospice at home service did not develop, yet by studying the history this revealed that it was the intention of the pioneers to provide it. However, there was some dissent over the introduction of the proposals because of concerns about services becoming disjointed if they were not under the oversight of general practitioners, and these social and historical factors impacted to shape services (see chapter 4). Therefore the study also answered research questions (e), (i), (k) and (m) (see 3.9) and progressed towards addressing the fourth aim.

Over time broader social, professional and political mechanisms impacted on the development of local cancer services in three key ways. First, the general public was discontented with the paucity of services, various patient groups emerged and this increased the social pressure for change (Bennett et al., 1996; McIllmurray, Gorst and Holdcroft, 1986; Overy and Tansey, 2012) (see chapter 1). This suggests that cancer support services developed as a response to the emotional and social needs of an increasingly challenging public (this overlaps with aim one above). Second, medical oncology developed as a specialism and the Association of Cancer Physicians was formed to represent medical oncologists. Subsequent strategy evolved that supported the development of oncology and cancer support services in the district (Association of Cancer Physicians, 2012; McIllmurray, 1987; McIllmurray and Holdcroft, 1993) (see chapters 1, 4 and 6). Third, by the end point of my study there was also a long term national plan for cancer and palliative care services. This advocated more of a patient centred

approach involving the family, more coordination of cancer services with palliative consultation from diagnosis, counselling/complementary therapy and self-help groups (Department of Health, 1995; Department of Health, 2000). Yet many at the local grass roots had practised like this since the beginning of the 1980s. It is possible that in the course of time, these wider contextual factors increased the respectability of oncology and cancer support services because they supported district expansion. Overall, this study has increased understandings about the development of cancer and end of life care provision over time and addressed the fourth aim and overarching research question.

7.3 Implications of my study

The study shows that despite the absence of national planning it was possible for local services to develop at a specific time because of individual factors as well as broader social, historical, professional, political and economic mechanisms. These services were comprehensive because there was collaboration between oncology, cancer support and palliative care. Furthermore, they were available from the time of diagnosis until the end of life, so they offered continuous care. Yet there were tensions in the beginning because services were so flexible and later as they became more structured. However, the findings cannot be taken as an indication that developments were analogous in other places; more research is needed involving different cohorts in the modern era.

7.4 What worked well and what did not in the research

There were various challenges during this research; some accounts were upsetting, particularly ones relating to the provision of compassionate care for those nearing the end of their lives. I shed some tears listening, reading, analysing and interpreting the reflections; I think this was because I could relate them to aspects of my own very close losses in life. I was conscious of the fact that so many people had been willing to spend time telling me about their experiences, and I wanted to do justice to their stories (see chapter 3). The method generated an amazing volume of recordings (just short of 44 hours), transcript material (1075 pages) and the analysis was time-consuming (see chapter 3). Yet these processes were necessary in order to get a fair story from a broad group (Berry, 2002; Curtis et al., 2002; Glaser and Strauss, 1967). I have

explained the challenges of snowball sampling; actors were socially connected therefore they often shared similar interests. Nevertheless, I found the method worked well because it soon recruited participants, although a couple became too ill to take part. Most of the interviews took place in participant's homes and this worked well, a few captured extraneous noises but I would have been unlikely to capture such personal accounts if I had not interviewed participants in the comfort of home surroundings. The analytical tables I created functioned well; they enabled the systematic gathering of extensive data and rigorous analysis to take place using constant comparison (Bowman and Singer, 2001; Thomas, 2005). I carried out this process as fully as possible in an attempt to generate a credible account, establish the validity of the data and ensure the study was rigorous (Spencer et al., 2003). The method and methodology complemented each other to demonstrate interpretative flexibility as services were initially very flexible (Pinch and Bijker, 1984). They became more structured as consensus formed and finally it was possible to make connections with broader contextual mechanisms to show that they impacted to shape the development of cancer and palliative care services.

I have explained that the interpretation of experiences in the generation of knowledge was subjective therefore it was important to consider what made me interpret things as I did. I reflected on theoretical influences during data collection and analysis and reported the process in a research diary consisting of scoping documents, reflective notes and analytical and interpretative tables (Malterud, 2002). I reflected on this during supervisory sessions and discussions (see chapter 3). There is no guarantee that another researcher would reach the same conclusions, it is likely they would bring their own interpretations affected by their own experiences (Goldenberg, 2005; Nicolson and McLaughlin, 1988). Using oral history to construct events in a time period posed challenges because of problems with memory. I found that combining the method with documentary sources was most helpful in clarifying dates of important events, and providing background context (Berry, 2002).

7.5 Other unresolved issues and limitations

I have mentioned that the main limitations of the study related to the time period and perhaps the place. With hindsight, in an ideal world I would have covered local cancer and palliative

care service development to present day, but that would have made the study far too large for a PhD thesis because I was restricted by time, finances and words. Nevertheless, we do not know what happened from 2000, the end point of my study to the present time. There is a gap in our knowledge and in my opinion, future research needs to look at this as a matter of priority so that we can increase our understanding of how needs and services changed during this period. A similar research design could be used. The work could be done by one researcher with administrative assistance (for example to type transcripts), but ideally it would be better to have a core team because they could collaborate and share ideas/experiences. Funding would be needed; a collaborative approach would be best because different organisations such as Help the Hospices, Marie Curie and the Department of Health have vested interests in the findings. I envisage that it would be feasible to produce a report within two years of being granted research ethics approval and funding. I anticipate the main refutation would be the cost of such a study, yet at the moment we do not know how local services have developed from 2000 to present day, or the extent to which policy created over the same period has shaped these services. Indeed, there may well be wider social and political mechanisms that have also impacted on the developments of cancer and palliative care services. A scholarly, historical study would provide an opportunity to uncover developments and make broader connections. Thus the implications of such a study would be of benefit to fund holders in the National Health Service, particularly those administering hospitals and clinical commissioning groups and charities (Help the Hospices, Macmillan Cancer Support and Marie Curie). It would also be of interest to anyone else engaged in this area of work such as academics, the ground force multidisciplinary team (general practitioners, consultants, community and hospice nurses, social workers) and patient advocacy groups.

I have explained that my work was possibly limited to the 'place', but there are no local studies of cancer and palliative care service development with which to compare these findings. Future research using a similar theoretical framework as described would provide an opportunity to build on my work to see if analogous findings arise, and to generate new research perspectives. This study did not capture patients or family voices because that was beyond its scope; similarly Clark et al (2005) did not include them either. Therefore a gap remains and future research is needed that involves patients and families experiences of cancer

and palliative care services so that we can learn more about their needs, what worked for them and what did not.

In addition, work is required to find out whether women experience social inequality that impacts on their needs at the end of life (see chapter 5). Occasionally the hospice provided a place of safety for women who had been in abusive relationships but kept it hidden until they were facing death, which was an unexpected finding. Further research should increase understandings of women's needs and how care might be provided to meet these.

Research is needed to explore how compassionate care is provided at the end of life in areas outside the cancer/palliative care arena because this should increase our understanding. Particularly as there is now strategy which aims to provide palliative care for all, wherever care takes place (Department of Health, 2008). This was beyond the scope of my work yet it will be important as we move towards an increasingly privatized health care system.

Concluding comments

In summary, this thesis focused on oral history accounts and revealed that historical, social, individual, political, economic and professional structures operated to shape the cancer and palliative care services. It has increased our understanding about what happened at a particular time, when new services were introduced in the absence of strategy and professional representation. Furthermore, it has revealed how some changes were relatively short lasting. For example, within 10 years of opening its doors the hospice was transformed into a specialist palliative care unit because of broader powerful social, professional and political mechanisms that impacted on palliative care. Moreover, this meant that the previously *tripartite* services became more independent as the links between them weakened. This history has ensured that the ground breaking work and contributions of Pippa Youren and Malcolm McIlmurray are recognized and not forgotten; this is the key thing that I would like people to take away from my thesis. It was the unique care, and all the other things that I have discussed coming together at a particular time that made the cancer and palliative care services develop as they did.

I have demonstrated that my work is original and makes a key contribution because it revealed the details of how local cancer and palliative care services developed in a *tripartite* way. In addition it uncovered tension at times. It also showed that social constructionism was useful in increasing understandings of oral history accounts because of shared epistemological constructs. The macro level revealed great flexibility when the services started, in the course of time they became more structured as policy evolved to confirm consensus about approaches (Pinch and Bijker, 1984). Furthermore, at the micro level oral history accounts coupled with aspects of social constructionism methodology uncovered what compassion meant, and how compassionate care was provided which increased our understandings (Cox, no date; Firth-Cozen and Cornwell, 2009; Kearney, no date; Larkin, 2011) (see chapter 5). I found these compassionate accounts to be inspirational, they gave me the drive to carry on through periods of exhaustion because I was determined to ensure these stories were told.

Before this study there was no scholarly research on how local cancer *and* palliative care services (together) have developed. Although a small number of researchers had used oral history to explore the macro level of cancer and hospice evolution, or used written accounts about developing cancer support services at the micro level (Clark et al., 2005; Small, 2000; Soothill and Thomas, 1998) (see chapter 1). I have indicated my awareness of the limits to the project; my interpretation of local developments and the wider context is one interpretation, it is possible there are others (Craggs and King, 2013; Murray, 2011). My own study will be situated as a historical piece of work – a base for increasing understandings about how cancer and palliative care services developed as they did, at a particular time and the wider mechanisms that shaped them.

Thesis word count: 81,781 words, excluding appendices and Bibliography.

APPENDIX 1

20 April 2010

Dear

Re: Invitation to participate in research

I am undertaking a doctoral degree at the University of Glasgow. As part of my studies I am conducting some research about how Lancaster and district has developed its cancer and palliative care services over time. Professor David Clark, (Director of the University of Glasgow Crichton Campus) and Professor Nick Watson (of the Faculty of Law, Business and Social Sciences at the University of Glasgow) are supervising my study. Professor Clark is an internationally recognised expert on end of life care with many years experience in research and teaching in the field.

I am particularly interested in speaking to you because I understand that as a health care professional you have had experience of caring for patients with life-limiting illnesses in the Lancaster area. I attach an information sheet setting out the details of the study and what will be involved, together with a consent and clearance form for you to consider.

If you feel that you may be able to help and would be willing to participate in the research by taking part in an interview about your experiences please contact me on 01524 65728 and I will be pleased to arrange an interview when I can see you to discuss the study and what it will involve. I should like to thank you for taking the time to consider this letter and I look forward to hearing from you.

Yours sincerely

Sara Denver RGN, BSc (hons), Dip Law, Postgrad Dip Legal Practice, solicitor, doctoral research student.

APPENDIX 2

INFORMATION SHEET

You are invited to take part in a research project as part of my doctoral studies in the Faculty of Law, Business and Social Sciences at the University of Glasgow. Before you decide it is important to understand why the research is being done and what it will involve. Please read this information carefully and take time to decide whether you wish to take part. The study will investigate how Lancaster and district has developed its cancer and palliative care services - there is little understanding of how these develop in their local contexts. A study in one locality will shed light on this and lead to a greater understanding of how patients and their families can be supported in future, particularly in the context of emerging national policy (End of Life Care Strategy 2008) and government commitment to improving such services within the NHS. This is an area that has been neglected by researchers and I am not aware of another similar study.

I have approached you because of your background as a health care professional in the Lancaster area. It is envisaged that approximately 30 other participants (health care professionals) will be studied. I would be very grateful if you would take part but it is up to you to decide whether or not to participate. If you refuse there will be no penalty or loss of benefits to which you are otherwise entitled. If you decide to take part you are free to withdraw at any time. If you take part you will be given this information sheet to keep (and you will be asked to sign a consent and clearance form with depository instructions). If you take part in the research this will involve participation in an interview that will last about 60-90 minutes. The possible disadvantages of taking part may be inconvenience. In order to minimise this I will arrange an interview at a time and place convenient for you. It is expected that one interview will be required but several may be needed if you have a lot of information.

Interviews will be recorded and transcribed as soon as possible. A copy of the transcription will be made available. In accordance with the recommendations of the Oral History Society (2009) you will be credited for your contribution. This means that the data will not be anonymised and you will be identifiable (by name) in the

recording, transcript and any reports /publications containing data from your interview. However, if you do not wish to be identified I will ensure that data from your interview is anonymised (by removing your name). In the unlikely event that you were to lose capacity during the research, you would be withdrawn and subject to ethical approval, data already collected would be retained in identifiable form and used in this research and thereafter preserved as a public reference source for use in research, education, lectures and broadcasting.

During the study information about your personal contact details (i.e. your name, telephone number and address) will be kept confidential and will be stored in a locked cupboard and/or on a password protected computer. At the end of the study this information will be destroyed. Data collected during the interview (recordings and hand written notes) will also be stored in a locked cupboard and/or password-protected computer. At the end of the study your contribution (recording and transcript) will be preserved as a permanent public reference resource for use in research, publication, education, lectures and broadcasting and will be added to the Hospice History Project collections, an approved archive repository at the Henry Duncan Library, University of Glasgow (Crichton University Campus, Dumfries, DG1 4ZL). You will be invited to sign a consent and clearance form with depository instructions. By signing this form you are consenting to participate in this research study and assigning copyright to the custodians at the Henry Duncan Library. This will ensure that the interview data is preserved in secure conditions and this will prevent unauthorised copying of material.

If you have any queries about this study, please feel free to contact:

- Sara Denver, The Gatehouse, Parkgate Drive, Standen Park, Lancaster, LA1 3FN. Telephone: 01524 65728
- Professor David Clark, Director of University of Glasgow, Rutherford/McCowan Building, Crichton University Campus, Dumfries, DG1 4ZL. Telephone 01387 702043.
- Professor Nick Watson, Faculty of Law, Business and Social Science, Department of Sociology, Anthropology and Applied Social Sciences,

University of Glasgow, Adam Smith Building, Bute Gardens, Glasgow, G12
8RT. Telephone 0141 3303916.

Signed:.....
.....
.....

(Please sign and type your name and contact details here)

APPENDIX 3

CONSENT, CLEARANCE NOTE AND DEPOSITORY INSTRUCTIONS

Version 1.0. 20 March 2010

I understand that Sara Denver
(name of researcher)

is collecting data in the form of Taped interviews

for use in an academic research project at the University of Glasgow. Details of the study are set out in the attached information sheet. Please read this carefully.

The purpose of this deposit agreement is to ensure that your contribution can be added to the collections of an approved archives repository in strict accordance with your wishes. All material will be preserved as a permanent public reference resource for use in research, publication, education, lectures and broadcasting. A summary of your interview and the full transcription of it may be included in the Hospice History Project Archive at Henry Duncan Library, University of Glasgow, Crichton University Campus, Dumfries, DG1 4ZL.

If you wish to limit public access to your contribution for a period of years (up to a maximum of 30 years) please state these conditions.

.....
.....

I give my consent to the use of data for the above mentioned purposes and I hereby assign the copyright in my contribution to the Hospice History Project Archive at Henry Duncan Library

Signed Date

Address

.....

Signed (on behalf of Henry Duncan Library) Date

.....

Henry Duncan Library
University of Glasgow
Crichton University Campus
Dumfries
DG1 4ZL
Telephone: 01387702043

Office use only:

Full Name

Ref. No

Researcher's name:

Sara Denver, the Gatehouse, Parkgate Drive, Standen Park, Lancaster, LA1 3FN.

Telephone 01524 65728.

Supervisor's name:

Prof David Clark

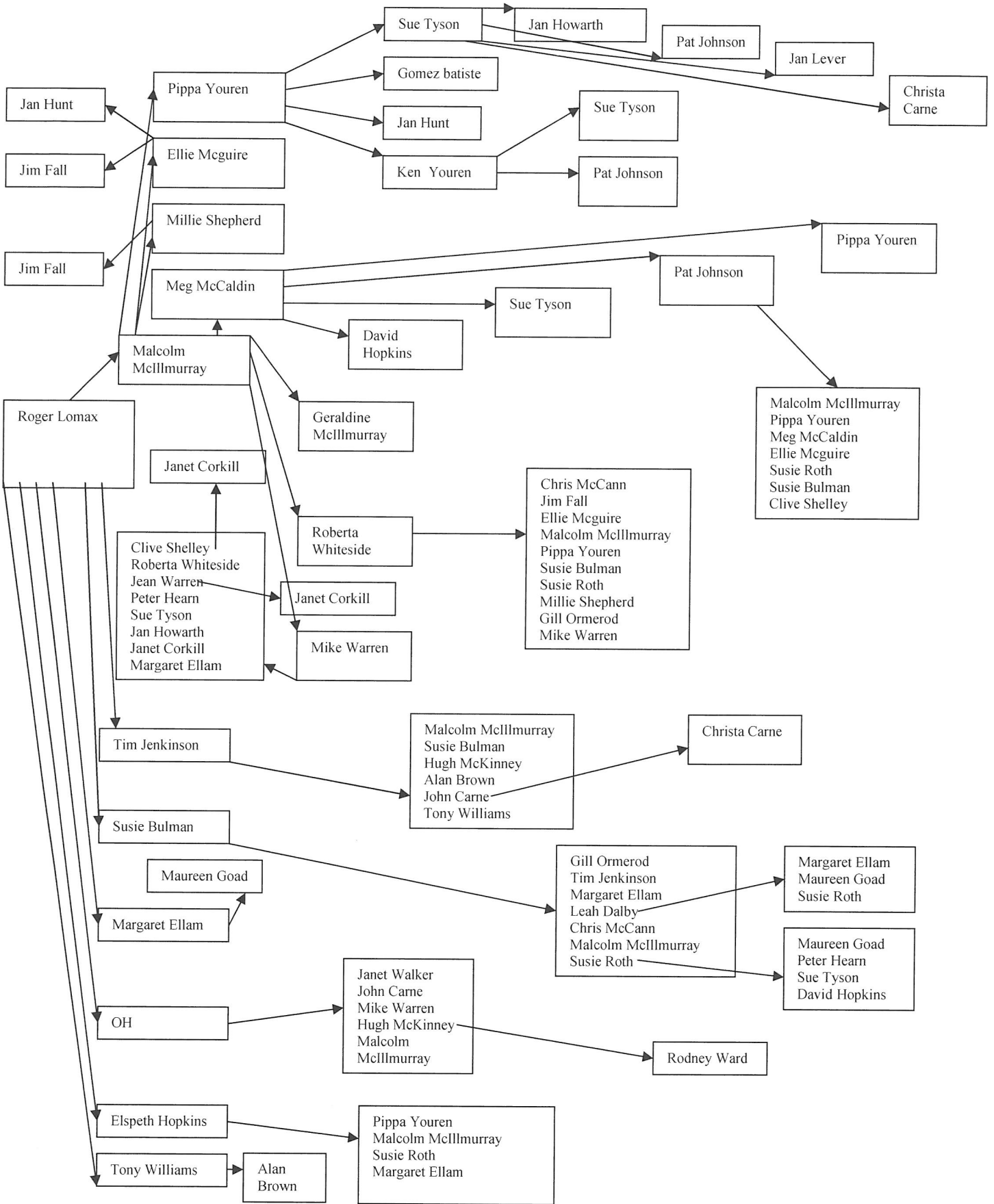
Department address: Director of the University of Glasgow, Rutherford McCowan

Building, Crichton University Campus, Dumfries, DG1 4ZL. Telephone 01387702043.

Prof Nick Watson, Faculty of Law, Business and Social Sciences, University of Glasgow,

Adam Smith Building, Bute Gardens, Glasgow, G12 8RT

APPENDIX 4. Figure 2: Number of times prospective participants were put forward



APPENDIX 5

Participants' details

NAME	YEAR OF BIRTH	TRAINING	ROLE	PLACE WHERE PRACTISED	STARTING DATE IN AREA
P1		Cambridge and Westminster Medical School 1956-1959	GP	Lancaster	1964
P2		Liverpool Medical School 1951-1956	GP	Lancaster	1968
P3		Royal Victoria Infirmary, Newcastle Nurse Training, Health Visitor	Breast Nurse	Community, CancerCare and Hospice	1983
P4		St Thomas's Nurse Training 1967-1970. Health Visitor	Volunteer then Sister of Day Care and Deputy Matron	Hospice	1977
P5		The Royal London Hospital 1962-1968	Consultant Oncologist	Hospital, Community, Hospice and CancerCare	1978
P6		Leeds University Medical	GP	Lancaster	1962

		School 1951-1957			
P7		Oxford and Guys Medical School 1958-1964	GP	Lancaster	1967
P8		Hampstead General 1957-1960 Nurse Training. District Nurse Health Visitor	Cancer Support Health Visitor	Hospital. Lancaster ('Drop ins' and home), CancerCare and Hospice	1979
P9		Wrightington Pre-Nurse Training 1957-1958. SRN Midwifery District Nurse	Cancer Support Nurse, and Macmillan Nurse	Hospital, Kendal ('Drop ins' and home), CancerCare and Hospice	1984
P10		Leeds University Medical School 1962-1967	GP	Milnthorpe, St John of God Hospital and Hospice	1969
P11		Woodlands Orthopaedic Bradford Royal Trainee Nurse 1957-1959.	Theatre Sister. Medical Ward Sister. Practice District Nursing Sister	Hospital then Community	1963
P12		Bath Hospital 1984-1987 Physiotherapy Training	Physiotherapist	Hospice	1995
P13		Froebel	Volunteer at	CancerCare	1982

		London Nursery Nurse Westmorland EN Training 1982	CancerCare drop in then later on Matron	Drop in and Hospice	
P14		Local Business	Volunteer	CancerCare, 'Drop in' at Morecambe and Hospice	1987
P15		1976-78 Chemistry Manchester University. SRN Training. Manchester Royal	Nurse, volunteer then counsellor	CancerCare	1989
P16		Nurse training Cumberland Infirmary 1953	Oncology Ward Sister	Hospital then Hospice Day Care	1987
P17		Nottingham University	Volunteer, relaxation therapist, General Manager and hypnotherapist	CancerCare	1984
P18		Leeds Infirmary	Volunteer and trained nurse	Hospice	1984
P19		Middlesex Hospital	Cancer Support Health Visitor	Hospital, Morecambe Bay ('Drop ins' and home), CancerCare and Hospice	1988

P20		Leeds	Palliative Care Consultant	Hospice and Hospital	1994
P21		Oxford	GP	Morecambe	1962
P22		St Andrews	GP	Lancaster	1963
P23		Lancaster University Environmental Science	General Manager	Hospice and CancerCare then Hospice only	2000
P24		Hope Hospital, Salford 1968 Nurse Training, Midwifery Training, London. Health Visitor Training.	Macmillan Nurse	Hospice, Hospital, CancerCare and Community 'Drop in'.	1994 became Macmillan nurse
P25		Domestic Science, Battersea Domestic Science College	Volunteer	Lancaster area, Hospice	1978
P26		Lancaster University Social Work	Medical Social Worker	Hospital and Community then hospice	1986
P27		Local Business	Volunteer then General Manager	CancerCare	1992
P28		S.E.N. Q.E Birmingham 1971. Oncology Marsden	Oncology Ward Sister	Kendal Hospital	1996

		London 1979. SRN Training Peterborough.			
P29		Economics Cambridge	Treasurer of Trustees	Hospice	1982
P30		Local Business	Typist then Transport and Finance Manager	CancerCare	1990
P31			Secretary	St John of God Hospital then Hospice	1983
P32		Local Business	Volunteer and Administrator	CancerCare	1990 volunteer at CancerCare then Administrator
P33		Religious Studies Lancaster University	Hypnotherapist	CancerCare	
P34		Paediatric Nurse Training 1952 Dressden and 1958 Carshalton	Volunteer and trained nurse	Hospice	1952 paed - iatric nurse training, 1989 Hospice Day Care
P35		MD	General Manager	CancerCare and Hospice	1992

Table 6 Quantum of transcripts from the Hospice History Project (1995)

	ESTIMATED QUANTUM OF INTERVIEWS
Number of participants	9
Number of recording hours	7 hours
Shortest interview time	20 minutes
Longest interview time	1 hour 58 minutes
Total number of pages of transcripts	165
Shortest transcript	6 pages
Longest transcript	47 pages

APPENDIX 7

List of broad topics for discussion during interview

- a) Place of birth, religion and family life
- b) When did individuals choose their occupation and why?
- c) What brought individuals to Lancaster and when?
- d) How did individuals come to be involved in cancer and palliative care?
- e) What was the philosophy of care?
- f) Did they feel part of something unique and special?
- g) How was pain managed?
- h) What links and bonds were forged between/across organisations?
- i) Paths not taken
- j) Charismatic leaders
- k) Routinization and bureaucracy
- l) Research and education
- m) Changes and challenges
- n) Anything else

The above topics have been adapted from:

Wright, M. (2004) *Interviews: General Guidelines*. International Observatory on End of Life Care, Lancaster University.

APPENDIX 8

Interview Transcript Extracts

Date: 20th November 2010

Voice file name: InterviewSR1.WMA

Colour Codes:

Yellow - From scratch to routine

Green – Philosophy of care and practice

Pink – Connected networks and charisma

Blue – Struggles

Orange – Across organisations

R: ...I did my training there... a bit shocking really. I found that hospitals were very, very institutionalised places and I thought that this really was not, I didn't think it would fit in with who I was really. But anyway I'd stuck it out and decided to do it.

I: **Sorry, can I just ask you, when you say it was institutionalised, could you just explain a little bit more about what you mean about that?**

R: What I mean about that?

I: **Yes.**

R: Well, like you're hierarchical, very hierarchical, so there was like, you know, there was very clear roles as to, you know, the consultant, the doctor, the entourage which goes round with the ward round you know. And if one was an enrolled nurse status, you know, like, "Nurse, stop doing what you're doing, go and clean the sluices," you know, that kind of thing. So I just felt like it wasn't a system that I was particularly naturally keen on or drawn to, as a system really. And there was not enough time to talk to the patients, which seemed to me to be hugely significant, and when people were frightened for operations, because it was a generic training so I was, surgical, medical, you know, all the different wards.

I: **Right.**

R: And I just felt like, you know, the importance, I mean I was an older person I suppose, I would have been 38, and I was just thinking that people needed more time to come to terms with their illness, rather than have kind of what just felt like quite, well particularly the surgical wards, you know, they were getting people ready for surgery. I mean you know you wouldn't ask them how they felt about it, because there wasn't the time, it was a conveyor belt atmosphere.

I: **Sure.**

R: ...I think that was just how it was. So I guess I was always somebody who thought talking to people was a good idea...I was on night duty and night duty, you have a little bit more time to talk.

I: Yes...

R: He was an educationalist. In the night, you know, one was able to spend time talking to people more and I remember talking to...about how he felt and how things were and his life as an educationalist. He was a very important educationalist: he was an Inspector of Education and things like that. And we got on really well together and it was a moment of, kind of, thinking, but he was an extremely poorly gentleman

I: okay

R: ...I mean he was living his life in that moment but he was very poorly. Anyway, there he was doing tremendously well and I thought, 'Gosh, cancer...really interesting you know.' So I began to be a bit interested in cancer patients and prognoses and how things might work, and I suppose the fact that we had...and I had had very honest conversations about the meaning of life and probably, religion or the lack of it, he wasn't religious either, as wasn't I...

...I had actually gone to the very beginning, not the very, very beginning, but the second or third meeting of CancerCare

I: right

R: which was a meal, which was, it was a meal in Ryelands Park and it was a, kind of, a mixture of patients and relatives and Professor McIlmurray and Pippa Holdcroft. Pippa was hugely significant, and the dietician who was Sue Lupson. These were all people who were there. And I'd just gone because I thought, "I think I'm just interested to know what's going on with this CancerCare." And I was put next to Malcolm McIlmurray...but I, kind of, knew who he was. And we just got chatting and he was talking about the beginning of CancerCare and he said, "What we're hoping to do is we're hoping to do swimming at the Capenwray Swimming Pool."

I: Oh, right.

R: He said, "But we really need to find somebody who can drive a minibus." And I said, "Oh, well I can drive a minibus." Because I learnt to drive on a Ford Transit van

I: **right**

R: and I used to drive children to Quernmore School, that was one of the things that I did. So he said, "Excellent, excellent, right, well you can drive the minibus." (Laughter). So I thought, 'Oh, this is good.' So I thought that would be interesting and I would meet a group of people at the hospice and take them to Capernwray, this was in an evening. So that was like my first involvement with CancerCare.

R: And in the creation of that, Malcolm asked me did I know any people... Glyn and his wife Joyce were like, one of the very first people who came to the drop-in and they knew other people and it was just a small little group of people.

R: ... I would arrive to lay it all out, you know, get the tables out and that, put tablecloths on, and I'd always take fresh flowers..

I: **And was your work at CancerCare as a voluntary?**

R: CancerCare was completely voluntary

I: **yes, right okay**

R: ...to work at the hospice. And I said, "I would really like to work here but I must always have Thursday off, because I'm running the CancerCare drop-in." So it must have happened before that.

R: ... It felt like the meaning of why I had become a nurse was emerging really, in a very, well, serendipitous kind of way you know

I **yes**

R and I felt so excited to be involved with the beginning's of CancerCare and we had a conference and we had the monthly meeting once a month down at the hospice, where people came. And the drop-in at Kendal just grew and grew. So we ended up with 80 people

R: ... when I was involved with Ellie at the very beginning, we were the face of CancerCare in Kendal so, so we were able to be the support for patients and their families there. And it was quite wonderful really – it was.

I: **Tell me a little bit about that.**

R: Well, as I said, I did actually write something... It started in this very, very small way and what happened was, is people would come through the door, very anxious...what would their lives be like, maybe they'd just had a diagnosis, maybe they were told now they need to go down for radiotherapy, down at that point it was actually down to Manchester.

And people come through the door and I would talk to them and I would say, "Would you like to meet somebody else who's actually, they've just finished their treatment at Manchester?" And they'd say, "Oh, that'd be wonderful." So then I would go to the other person and say, "Mrs so and so is going to be going down to Manchester," obviously with the agreement of everybody to share this knowledge. So then I'd put them together and of course, my job was done in a way. It was, it was to do with connecting people. It was to do with finding the person who would be best for that particular person you know.

It was magical really, and of course, we were able to, if people wanted, we had got a masseur, who sadly died, Lizzy Watson

I **oh right**

R was the first masseur, and Meg McCaldin would have been the, she would have been a therapist in those days, and we were able to offer, that people could have that kind of support down at Slynedales

I: oh right, okay

R: ... when they came, then they would get the sense of being part of a community and I think I called this little thing that I wrote, 'In The Same Boat' and it felt very much that people were in the same boat

I yes

R And they derived a sense of community and camaraderie and realised that after a diagnosis of cancer there is a life to be lived. So it was absolutely a thrilling, kind of, experience to be part of all of that.

R: ...it just shows the necessity for change, although respecting very much the kind of pioneering aspects of those original people, which was that when I first went as a nurse it emerged that you didn't get a holiday, a paid holiday, for the first year.

I: Right.

R: ... there wasn't a pension scheme at all.

I Oh right.

R In part, you see, that would have been to do with the fact that the religious sisters, they lived in a community just down the road, and of course in the fullness of time, when they would retire, they would be cared for by their religious community. So things like, kind of, you know working practices of legislation didn't really come into it as much, you know? So, that you did have a tremendous sense of kind of dedication really. And there were lots of positive aspects of that, but of course, in this changing world you really need to be thinking about pensions for young working people, and you need to be thinking about paid holidays.

APPENDIX 9

Quantification of documents – general (including Cancer support services)

DOCUMENTARY SOURCES	QUANTUM OF DOCUMENTS
Books (About health care practitioners, relatives and patients' experiences and perspectives in the local area)	<p>Dreams, Reflections and Memories (110 pages)</p> <p>Jimmy No Time To Die (214 pages)</p> <p>Now I Can Tell (117 pages of poems)</p> <p>The Emotional Cancer Journey (79 pages)</p> <p>Cancer in Young Adults (179 pages)</p>
<p>JOURNAL ARTICLES RELATING TO CANCER AND PALLIATIVE CARE SERVICES IN LANCASTER AND DISTRICT</p> <p>(Lancaster and Westmorland Medical Journal, MBMJ, British Journal of Cancer, Health Visitor, the Journal, Cancer Support Nurse, New Society, Palliative Medicine, Pulse of Medicine, Journal of the Royal College of Physicians, British Medical Journal, Journal of Cancer Care, European Journal of Cancer Care)</p>	<p>19 DOCUMENTS (64 pages)</p> <p>(Covering: Psychosocial, Behavioural and Communication Research in Oncology, 70 years of General Practice, the role of the medical social worker, developing a comprehensive service for patients with cancer, role of the Health Visitor in oncology, ward 3 annexe, Supportive Care in a District Service, The Art of Dying, Questions of Training, Cancer Centres Need to be Easily Accessible, Report of a Lancaster Project, District Cancer Physicians, A National Survey, A Comprehensive Service in a District General Hospital, Cancer Care of the Elderly, Cancer Support Nurses, Medical Oncology)</p>
MINUTES OF MANAGEMENT MEETINGS AT CANCERCARE 1984-1992	74 DOCUMENTS (370 pages)
MINUTES OF ADMINISTRATION AND SERVICES MEETINGS AT	44 DOCUMENTS (220 pages)

CANCERCARE 1989-1992	
MINUTES OF MEETINGS AT ST JOHN'S HOSPICE 1985-2000	About 180 documents (see St John's Minutes)
THE DEVELOPMENT OF DISTRICT SERVICES FOR CANCER PATIENTS	3 pages
IMAGES AND VIDEO FILM	20 PHOTOGRAPHS, 1 CD ROM, 1 video on cancer and palliative care
CANCERCARE BUSINESS PLANS	6
ST JOHN'S NEWSLETTER 'IN-TOUCH' 1987-1990	12 DOCUMENTS
ST JOHN'S AND CANCERCARE RAPPORT MAGAZINE 1986-2000	56 DOCUMENTS (about 896 pages)
CANCERCARE WRITTEN CONSTITUTION	4 pages
CANCERCARE ANNUAL REPORTS	20 DOCUMENTS (400 pages)
CANCERCARE POLICIES	20 pages
PROJECTS DONE AT CANCERCARE AND ABOUT ST JOHN'S HOSPICE	47 pages

EARLY CANCERCARE INFORMATION LEAFLETS	4 pages
PROPOSED DEVELOPMENTS AT SLYNEDALES	2 pages
SLYNEDALES APPEAL DOCUMENTS	15 pages
CANCERCARE CONFERENCES LISTS OF NATIONAL SPEAKERS	12 pages
ST JOHN'S AND CANCERCARE PERSONNEL STRUCTURE (UNDATED FROM THE VERY EARLY DAYS)	5 pages
CASE STUDY IN THE COMMUNITY 1979	5 pages
NURSES PLAN FOR ONCOLOGY SERVICES AT KENDAL (undated). ANNUAL REPORT ONCOLOGY NURSING SERVICE WESTMORLAND GENERAL HOSPITAL 1993. HOSPITAL INFORMATION BOOKLET 1992. ANNUAL REPORT 1996-1997.	9 pages
REFLECTIONS ON THE HISTORY OF CANCERCARE	8 pages

SLYNEDALES PHILOSOPHY	1 page
SLYNEDALES RENOVATION VOLUNTEERS	3 pages
CANCERCARE THE FIRST 10 YEARS.	2 pages
HISTORY OF CANCERCARE	4 pages
A HISTORY OF CANCERCARE 1996	12 pages
A HISTORY OF CANCERCARE PART 2	8 pages
ST JOHN'S HOSPICE NOTES ON THE BEGINNINGS OF THE HOSPICE AND CANCERCARE	3 pages
A HISTORY OF THE HOSPICE 1976-1986	3 pages (Lucy Parker)
A HISTORY OF THE HOSPICE 1985	3 pages (Mike Warren)
MORECAMBE BAY PALLIATIVE CARE UNIT NW NHS EXECUTIVE CANCER PROJECT TEAM 1999	7 pages
ST JOHN'S NURSING PHILOSOPHY 1994	1 page
ST JOHN'S HOSPICE JOB SPECIFICATION – MATRON 1994 and 1999	8 pages
SHARING IN SOUL PAIN AINE	1 page

COX	
DEED OF DECLARATION OF TRUST ST JOHN'S HOSPICE	7 pages
LANCASHIRE AND LAKELAND CONTINUING CARE NHS TRUST REGISTRATION OF CHARITIES	2 pages
DEEDS OF APPOINTMENT OF TRUSTEES	23 pages
CHARITY COMMISSION REPORT	2 pages
ST JOHN'S CONSTITUTION OF MANAGEMENT COMMITTEE	9 pages
THE NORTH LANCASHIRE AND LAKELAND CONTINUING CARE TRUST – SPECIAL REPORT	18 pages
REVIEW OF CANCER SERVICES IN ENGLAND AND WALES 1994	37 pages

APPENDIX 10

Quantification of documents held at St John's Hospice

TYPE OF DOCUMENT	QUANTIFICATION OF DOCUMENTS AT ST JOHN'S HOSPICE
MULTIPLE SCLEROSIS SOCIETY FOLDER	Correspondence from early 1980s with Lucy Parker, MSW and the MS Society. Applications for grants. Correspondence from Dr Hay attempting to set up a hospice in the late 1970s. Correspondence with potential benefactors. Local newspaper articles.
MULTIPLE SCLEROSIS FOLDER	Correspondence 1981-1987.
SOUTH CUMBRIA CORRESPONDENCE – AGREEMENTS	Admission lists to hospice in 1986. Correspondence and service agreements.
JOINT TRUSTEES FOLDER	Minutes 1990s
DECLARATION OF TRUST FOLDER	Deeds
MANAGEMENT MINUTES FOLDER	1990s
ORANGE FOLDER	Minutes from 1990s
TRANSPARENT FILE	Contracts for palliative care services 1990s.
LANCASTER HEALTH AUTHORITY FOLDER	Correspondence.

TRUSTEE MANAGEMENT MEETINGS FOLDER	Minutes 1990s-2000.
AIREDALE FOLDER	Correspondence 1990s.
YELLOW FOLDER	Correspondence 1990s.
LANCASTER HEALTH AUTHORITY SERVICE AGREEMENTS FOLDER	1992-1995.
MANAGEMENT COMMITTEE FOLDER	Correspondence, constitution of management committee, declaration of trust deeds 1980-1993.
UNNAMED FOLDER	Minutes 1980-1985.
UNNAMED FOLDER	Minutes 1986-1987.
MEETING FOLDER 1988-1989	Minutes 1986-1987.
MINUTES FOLDER	Minutes 1988-1989.
1992-1993 FOLDER	Minutes 1992-1993. Papers 1991
1996 FOLDER	Minutes 1996.
NO NAME FOLDER	Minutes 1992-1993.
NO NAME FOLDER	Minutes 1989-1991.
NO NAME FOLDER	Minutes 1994-1995.
BLUE FILE TRUSTEE MINUTES	Minutes – various.

APPENDIX 11

Thematic analysis – coding the transcripts - extracts

CHARISMA	FROM SCRATCH TO ROUTINE	MOVING ACROSS ORGANIZATIONS	PHILOSOPHY	STRUGGLES
Charismatic Leaders	Starting out of the absence of anything Biggest advantage – there was nothing Nowhere special for cancer patients to be seen	This relates to patients, family and former health carers accessing care at various places interchangeably	Philosophy of care Philosophy of practice/practises Refer to Appendix 12 for details	Difficulties Distressing Power Responsibility ‘Nerve wracking’ Scary Tricky
Driven Dynamic	Perceived psychological and geographical I need to do something for an area not wealthy. Horrendous journey’s to Christie Huge area	Care provided at home, CancerCare, St John of God, St John’s hospice and hospital Nurses working in drop-ins as well as on hospice wards		Nerves Autonomy Resistance Greater acceptance Nurses did what doctor told them Nurses-v-doctors
Impulsive Intuitive	Rurality difficult	Patient’s at different ‘stages on the cancer		Nurses-v-nurses

6 th sense Talk to people	How it felt to be part of the organization /group: Breaking new ground Enthusiastic All working for this wonderful goal Among the first in country to treat holistically	journey' accessing these organizations (e.g. some physically well but psychologically very anxious following new cancer diagnosis and other individuals at the end of their life).		Doctors-v-nurses Therapists-v-nurses Volunteers-v-nurses Credibility Confidence Confidentiality Apprehensive Relationships never easy
Definite ideas	Lovely Happy Sad Special Experimental Play it by ear Great success	Care provided from time of diagnosis to 'cure' or 'end of life'		Doctor led Courage Fear of doing something wrong Distressing hierachy
Take on anything	Nice atmosphere (Links between CancerCare and Hospice)	Caring for individuals at any stage of their illness trajectory if they physically, psychologically, socially or spiritually required it.		Conflict Gender struggles Suspicious Hostility Creepy Orthodoxy

APPENDIX 12

Thematic analysis: coding of the transcripts relating to philosophy - extracts

PHILOSOPHY OF CARE	PHILOSOPHY OF PRACTICE
Holistic care Total care Safe place	Personal past experiences leading individuals into cancer and palliative care work
Palliative care is like life – it is treating people with dignity and showing them you care Kind	Past experience of cancer care and end of life care increases understanding of how patients feel and what the illness is actually meaning for them
Good care Love	Serendipitous encounters in medical/nursing practice
Mechanistic Physical care Time Compassion Caring	Personal experiences of caring for individuals at the end of life (i.e. to capture practices demonstrating how cancer and palliative care was done, what was important)
Thoughtful Range of perspectives (i.e. patients, families and staff)	Talking about past experiences was not something health care practitioners do very often
Important to have people who are different	Undermined people's confidence to go back home
Counselling Denial of death	Night duty gave some practitioners an opportunity to talk to individual patients
Honesty over time Death part of life Truth telling Giving up the will to live Secrecy Pretence Euphemisms	Working with death changes your life – you get a better outlook for the rest of your life
Silence	Staff consistent

Collusion of anonymity Belief in patients having the right to decide Curative	Nuns practised in a manner where there was 'an openness about death'
Incurables Excellent nursing home type care Length of stay in hospice	The dying were nursed openly in the same room as patients who were not dying
Able bodied End of life Palliative care Specialized palliative care	After death the individual would be pushed in their bed from the ward to the mortuary in an open manner. They would be seen by anyone passing.
Specialization Professionalization Spiritual care Psychological care	The hospice was designed in such a way that those who had died on the ward were pushed in their bed through the dining room to get to the mortuary
Reassure Relieve symptoms Compassion Fear Crisis	Nuns were 'confident about death' and this practice instilled confidence in hospice staff so that they were not nervous of death and could sit with people who were dying
Self referral	Look at what can be done not what can't
Empowerment Confident patients	Having a beautiful manner and positive approach
Acceptance of a wide range of perspectives (patients and staff)	Special approach
Pain: Physical Painful feelings Soul pain Pain control Brompton cocktail – local stories	'Being along side someone where they are at'. Being at the person's side

APPENDIX 13

Scratch to Routine

<p>NAME</p> <p>Initials</p>	<p>THEME – From Scratch to Routine</p> <p>(to allow content analysis/descriptive data analysis)</p>	<p>SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES</p> <p>(descriptive accounts of themes – what is going on here? Explanations for the data (theory))</p>	<p>REFLEXIVITY</p> <p>(What is it in my background and research interests that affect what I see and how I code this text?)</p>	<p>DOCUMENTS</p>
<p>HM p.49</p> <p>HM p.50</p>	<p>...the country made a massive decision to have only a limited number of cancer centres...this...meant travel and that can be difficult, particularly for people who require radiotherapy on a daily basis to go to Manchester and to come back again... ...but there would not be any hope really of these very, very expensive machines with expensive people running to be in every</p>	<p>Starting from scratch</p> <p>Oncology services how country developed oncology services – different to L/C as it was DGH</p> <p>Geographical challenges</p> <p>Reason radiotherapy never developed</p>	<p>I had made a decision that I wanted to tap into narratives that would ‘paint’ a picture of what it was like before any local specialist services developed</p>	<p>See what documents produced by Association of Cancer Physicians in 1980s say and The Calman-Hine Report</p>

	hospital.	in Lancaster - cost		
JC p.2	I first went to Silverdale...1983...they took about...half a	Reflections of a volunteer at St John of God	I am aware of these 'earlier' terminal care	Document written by Lucy Parker
JC p.3	dozen...that we would call palliative care patients now...usually people with cancer...they nursed them...till they died... So it was like a little beginning of the	indicate that there were 'signs' of hospice type care developing in the area even before the hospice was actually built in Lancaster	developments from interviews with Mike Warren, Jean Warren, GM, TJ	
JC p.4	hospice			
PY p.22	there were a lot of things about Lancaster that made life; (silence) I was going to say easier...One of the things is that there was nothing at all. If you go in to an area trying to set something up and there are already a lot of people all...doing their little thing, it can be difficult...when you walk in to a desert, all you needs a bit of water... Marvellous how it'll all come to bloom. So that was our biggest advantage	Starting from scratch made it 'easier' to set up cancer services – no need to create a paradigm shift although there were of course many challenges with some district nurses and GPs – see 'struggles' theme	I am aware from my interview with MM that services were easier to develop - as there was nothing (so nothing to change). However, the service brought a 'different' way of working and I am aware from other interviews there were difficulties. Some were unhappy with the 'cancer support nurse'/'oncologist'	See articles by MM and PY's book Dreams, Reflections, Memories

APPENDIX 14

Across Organisations

<p>NAME initials</p>	<p>THEME – Moving Across Organisations (to allow content analysis/descriptive data analysis)</p>	<p>SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES (descriptive accounts of themes – what is going on here? Explanations for the data (theory))</p>	<p>REFLEXIVITY (What is it in my background and research interests that affect what I see and how I code this text?)</p>	<p>DOCUMENTS</p>
<p>EM p.19</p>	<p>every Wednesday... there was a meeting at the hospice...GPs could come...Social workers...Macmillan nurses...Dr McIllmurray...Anyone connected in the care of these patients that we were sharing...would be gone through...then we would have lunch together...And the main reason for it, a total opportunity to discuss patients...So that was a huge link. And I could ring and</p>	<p>EM reflects on main advantage of moving ACROSS ORGANIZATIONS - multidisciplinary team sharing the same patients could come together and discuss their needs from social, physical, psychological and spiritual perspectives. Main purpose was to develop links - useful for getting advice whenever it was required</p>	<p>I am aware from other interviews that many individuals (although ‘employed’ in one organisation) actually ‘moved’ across organisations to access the best parts of services depending on what was needed and where people were being cared for – home, hospice,</p>	<p>See if there is any documentation at the hospice relating to the meetings See journal articles on the role of the cancer support nurse. Tony Williams talks about this and Chris McCann – see their interviews</p>

	take advice from them at any time		CancerCare, Drop-ins etc.	
JF p.9	they were more than happy. They used to facilitate it. They gave me rooms to work in. I have worked in Sister Aine's room before now and I remember many times. Whatever was necessary. They were fully...they couldn't have been more cooperative	Hypnotherapist moving across organisations – between CancerCare and hospice	I am aware that from interviews things changed over time and links were broken as hospice brought in its own therapists (see CS)	Refer to other interview transcripts on this Documents from the hospice on remaining separate (project)
SR1 p.10	I applied...to work at the hospice. And I said, "I would really like to work here but I must always have Thursday off, because I'm running the CancerCare drop-in."	Moving across organisations enabled Susie Roth to continue voluntary work at the drop-in and work at the hospice as well	I am interpreting this in this manner because I am aware from other interviews that many individuals were involved in several of the cancer and palliative care services	Refer to Dreams, reflections, Memories

APPENDIX 15

Philosophy of Care

NAME	THEME – philosophy of care (to allow content analysis/descriptive data analysis)	SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES (descriptive accounts of themes – what is going on here? Explanations for the data (theory))	REFLEXIVITY (What is it in my background and research interests that affect what I see and how I code this text?)	DOCUMENTS
Initials				
PY p.45	walking in somebody else’s shoes certainly can give you a better feel of what people are actually experiencing you know. I think sometimes we are reluctant to stop and think exactly how it feels for somebody else. You see nearly all over us involved in the work, I mean, Malcolm’s own mother, she died of cancer...my good	It seems that past experience of loss helped one see things from another person’s perspective Drawing on personal past experiences helped to see through someone else’s eyes and increase understanding of meaning for the individual pt by the carer	I am aware from interviews with Malcolm McIlm urray that in the beginning he found many cancer patients suffering psychologically – in a crisis and therefore CancerCare started out of this identified need so it would be important to have staff that were able to empathise	See Pippa’s book. See articles written by Roberta Whiteside, Ellie Mcguire, Elspeth Hopkins

	<p>friend Lizzie...it does enable you it gives you a window onto things...it gives you a better understanding of how people are feeling...is to see what is happening to this person, is actually meaning for them</p>			
<p>MW p.47</p>	<p>I think the biggest Change...still a long way from complete, is the recognition of the fact that people are entitled to, or deserve, to be treated with respect and dignity towards the end of their lives...I can't see why you can't apply that the rest of the time as well... That...is the big thing which the Independent Hospice Movement has brought to the community</p>	<p>Philosophy – taking hospice philosophy to a wider audience in the community</p>	<p>I am aware from my readings on the modern hospice movement about 'total care'/holistic philosophy starting from the grass roots and eventually being incorporated into national policy. Guidelines advocating palliative care for all regardless of diagnosis from the time of diagnosis.</p>	<p>National guidelines – terminal care/cancer care, Association of Cancer Physicians, Calman-Hine, The NHS Cancer Plan</p>

APPENDIX 16

Philosophy of Practice

NAME Initials	THEME – philosophy of practice (to allow content analysis/descriptive data analysis)	SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES (descriptive accounts of themes – what is going on here? Explanations for the data (theory))	REFLEXIVITY (What is it in my background and research interests that affect what I see and how I code this text?)	DOCUMENTS
Meg p.14	trying to find ways in which one could make their life easier, particularly through treatment. And that was where the therapy work came in because we gradually introduced on the one hand the group activities, which were particularly useful for people who were on their own...so they'd come to an art class because they were lonely...folk who have painted wonderful pictures at the end of their	Philosophy of CancerCare was to 'make things easier' Meaning of therapy to patients from Meg's experiences It addressed loneliness Art was used in conjunction with therapies and these changed and developed	I can see how people would be lonely if they lived alone and were ill – perhaps some felt lonely in their illness rather than because they were alone – it is possible to be surrounded by people but if they don't understand or you cannot talk	Have a look at Pippa's book and also interviews with Jim Fall and Gill Ormerod on therapies. Gill Ormerod's interview is interesting because it provides stories about the lives of some women facing death in abusive relationships. It has been locked away and never discussed before having
Meg p.15	life...jewellery...similarly...on the one hand you had that and on the other hand we were trying to			

	develop the key therapies which seemed to help people with anxiety or their physical problems connected...started with massage...Jim Fall...hypnotherapy...Alexander Technique		to them that is a form of loneliness too	counselling.
SR1 p.6	I was on night duty and night duty you have a little bit more time to talk There was a... particular patient...the Glyn Harris award...Glyn Harris was the man I met on the ward and he was ill...and I remember talking to Glynn about how he felt...and his life as an educationalist...and we got on really well together...it was a moment of...thinking but he was ...extremely poorly...but then I moved on to the next ward	Night duty provided this pupil nurse with more time to talk and address psychological needs (holistic care) Serendipitous personal encounter provides a glimpse into this individuals practice – information giving seems to have been important and building a good rapport with patients (would this help them to feel safe?) Discussions about the meaning of life for the particular individual Able to offer more holistic treatment than just chemotherapy – so able to provide complementary therapies	I am aware from my previous work in oncology and from my reading about Cicely Saunders' work that having time to really listen is a crucial factor in providing total care Glyn Harris became hugely significant in CancerCare later on and started the Award for creative writing	See PY's book and documents about CancerCare's Glyn Harris award

APPENDIX 17

Struggles

<p>NAME</p> <p>(Initials)</p>	<p>THEME</p> <p>Power/other Struggles</p> <p>(to allow content analysis/descriptive data analysis) (I have interpreted words in bold as relating to power struggles)</p>	<p>SUMMARIES OF SIMILARITIES OR DIFFERENCES RELATING TO CODES</p> <p>(Descriptive accounts of themes – what is going on here? Explanations for the data (theory))</p>	<p>REFLEXIVITY</p> <p>(What is it in my background and research interests that affect what I see and how I code this text?)</p>	<p>DOCUMENTS</p>
<p>PY p.49</p>	<p>figures that they worked on were like plaster of Paris figures, like stick figures...well people found that, you know cancer patients often go very...thin and of course this brought up a lot of...painful feelings</p> <p>great thing about Aine was that she would</p>	<p>Struggles getting some people to confront 'death' and talk about perspectives. PY has just mentioned some sculptors doing a project on 'the dying' at the hospice.</p> <p>There is overlap with philosophy on life and death and charisma.</p>	<p>I am aware from interviews with others that the sculptors were Norwegian (I have an article by Sr Aine on it) and the sculptures were controversial for some individuals</p>	<p>There is an article on this by Sister Aine</p>

<p>PY p.50</p>	<p>talk to people...very intuitive woman</p> <p>so of course, having that diffused, actually, people started talking about REAL feelings, so it actually turned out very beneficial</p> <p>it could have gone either way if...Aine hadn't been there...I wouldn't ...it's no good stirring things up unless somebody is there to...resolve the issues, talk it through...get to the bottom...Aine did do that</p> <p>the great thing too about things were out in the open and talked about, you know controversy isn't always bad.</p>	<p>Important to have Sr Aine around to talk to about perspectives on the sculptures.</p> <p>The story demonstrates that once the issue of dying was 'out in the open' it was essential to have an individual such as Sr Aine to talk to patients and relatives</p> <p>Controversial struggles have more than one perspective and on some occasions can work in a beneficial way – here it got some individuals to talk about themselves as they neared the end of their life</p>		
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APPENDIX 18

PUBLICATIONS

Some aspects of the study findings have been presented at the following conferences:

3 November 2009. I delivered a presentation at Maxwell Gillott Annual Business Conference: Medico-legal perspectives: advance statements and advance decisions in end of life care planning.

11 January 2010. I presented an outline of the study at: Presenting with Impact for PhD students. University of Glasgow.

15 March 2010. Publication of article: Denver, S. (2010). Guidelines in relation to assisted suicide: perspectives about end of life care. Simpson Millar LLP Legal News. 15 March.

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21 May 2011 - Elshieshields Postgraduate Symposium. I delivered a 30 minute presentation about: Development of Cancer and Palliative Care Services at Elshieshields Tower, Lochmaben, Scotland.

20 January 2012 - Doctoral studies in pain, palliative and end of life care: a one day seminar for students past, present and future. I delivered a 45-minute presentation about: An oral history of the development of cancer and palliative care services in one community in the North West of England.

University of Glasgow.

22 June 2012 - Postgraduate Day at Dalswinton House. I presented an update of: An oral history and documentary construction of the development of cancer and palliative care services in one community in the North West of England. Dalswinton House, Dumfries, Scotland.

21 June 2013 - Postgraduate Research Conference at the University of Glasgow.

The Crichton. I delivered a paper about experiences of developing cancer and palliative care services to a mixed audience.

17 October 2013- PhD Research Network Seminar International Observatory on End of Life Care. Lancaster University. I delivered a power point presentation of my study. Experiences of developing cancer and palliative care services – a historical study.

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