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Methodological challenges of developing a tool to measure patient recall and understanding from a Haematopoietic Stem Cell Transplantation (HSCT) consultation

and

Clinical Research Portfolio

Volume I

(Volume II bound separately)

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Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

September 2014

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1

Table of Contents

(Volume I)

Acknowledgments

CHAPTER ONE:

Systematic Review

Cancer patients experiences of using decisional support aids: a qualitative systematic review

Prepared in accordance with submission guidelines for The European

Journal of Cancer Care (See Appendix 1.1)

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ABSTRACT

This systematic review of qualitative studies investigates how cancer patients utilise Decision Aids (DA's). Meta-ethnography was used to identify and synthesise the studies. Articles published until April 2013 were searched in EMBASE, MEDLINE, CINAHL and PsychINFO. Relevant journal articles and reference lists were also hand-searched. Seven studies were identified for inclusion. Quality was assessed using a rating scale based on Walsh and Downe's (2006) quality rating framework. Four themes were identified: i) Knowledge (ii) Trust (iii) Purpose and (iv)Value. The present review highlights that information is gained predominantly from the clinicians involved in the patients care and supplemented by the internet to facilitate consultations, to research signs of cancer recurring and to validate treatment decisions. Regardless of type, information aids perceived as trustworthy and tailored to patient need are most beneficial to patients. The findings are discussed and recommendations made in relation to future research and how health care professionals can develop and incorporate DA use in clinical practice.

Keywords: Qualitative systematic review, lived experience, decision aid, cancer, quality of life.

INTRODUCTION

Improving the delivery of medical information for patients is an important element of Scottish health care policy. In order to achieve this, consideration has been given to understanding the experiences of those with cancer throughout the journey of their illness. Healthcare policies in the United Kingdom (UK): "NHS Scotland Quality Strategy - Putting People at the Heart of Our NHS" (Scottish Executive, 2010) and "Excellence and Equality: Liberating the NHS" (Department of Health, 2010) emphasise the need for modern cancer services to be designed in a patient centered way. Therefore, the needs, preferences and experiences of cancer patients ought to be central to any discussion, particularly in the context of introducing novel technologies and designing services (Ring et al. 2011).

There is a growing body of evidence indicating that more patients' wish to be actively involved in their treatment decision-making in a way which can take into consideration their personal values and preferences (O'Brien et al. 2009). More formally, this is known as "shared decision-making". This is an approach which lays emphasis on the patients as experts on their own health and treatment preferences, as well as on the need for communication and explanation regarding medical conditions and treatment being provided accurately and sensitively (Neuman et al. 2007). Shared decision-making can have vast implications for cancer patients and healthcare professionals and in relation to related healthcare outcomes such as, adherence to treatment, coping with the illness itself and overall quality of life (van der Meulen et al. 2007).

Typically, patients attend a medical consultation during which they are provided with information about the disease itself and treatment alternatives. The provision of such vital information is to help patients prepare for treatment but it can also cause patients confusion, anxiety and uncertainty where treatment options exist. Despite policy and empirical research suggesting positive benefits from patients being involved in their own care, perhaps surprisingly, the literature also reflects that not all people with various forms of cancer wish to participate in treatment decisions (Balmer, 2002). This suggests that a balanced, more accurate representation of the informational needs and unique illness experiences of cancer patients is necessary.

Background

The existing literature reflects Ley's seminal work (1988) in relation to understanding effective communication. This model conceptualises the relationship between memory, understanding and satisfaction as being central to a patient's adherence to treatment and their ability to recall information. It is estimated that 40% to 80% of medical information presented by health care professionals was forgotten immediately by patients; this was influenced by a combination of consultant (i.e. use of medical terminology) and patient factors (i.e. emotional state and older age) (Kessels, 2003). Similarly, the communication style of the consultant, as well as a patient's cognitive processes and anxiety are additional factors which have been shown to have an impact upon the patient's recollection and comprehension of medical information. Collectively, these factors may create emotionally distressing and challenging situations for patients. Consequently, in response, mechanisms of support have been developed and are available to assist patients during the management of their disease.

Decision/information Aid use in the cancer setting

The most commonly cited form of support used to enhance the transfer of information between health care providers and patients, and some aspect of decision-making, is the clinical decision/information aid (DA/DAs). The DA has shown to be effective across various clinical settings, including cancer (Watson and McKinstry, 2009). The information in a decision aid is typically presented visually, although the format may vary. In simplest form, a decision aid may be a pamphlet or additional information sought by the patient from within the multi-disciplinary team (MDT). There are other, more definitive, forms of decisional support- aids, including, interactive computer programmes, decision boards, videotaped interventions, consultation audiotape/CD, internet websites, structured interviews and nurse navigators. The cancer patient can also access support and medical information from other sources such as the internet, family members and friends (Rozmovits and Ziebland, 2004).

Typically, DAs are used as adjuncts to the clinical consultation to encourage a balanced encounter and to enhance the processing of potentially distressing medical information otherwise deemed difficult to take on board by patients (Thorne et al. 2005). Broadly speaking, the aim of using DAs is to enhance patient decision-making and involvement and thereby develop better relationships between healthcare providers and patients (Neuman et al. 2007, O'Brien et al. 2009).

7

Whilst it is beyond the scope of the present review to provide a detailed outline of varying definitions and description of DA use among the cancer population, the following quote captures the essence of DA use in clinical reality:

"'An intervention designed primarily to help patients (or patients and clinicians together) with making cancer-related health care decisions when options were available for screening, prevention and treatment, anxiety, decisional conflict, patient satisfaction and role in decision making". (p.975)

(O'Brien et al. 2009).

Consistent with O'Brien et al. (2009), Neuman and colleagues (2007) propose that, by describing the associated medical and psychological issues, decision aids facilitate patient-driven decision-making based upon patients' values and preferences. In view of the policy and empirical support for decision aid use in the clinical setting, the remainder of this review will briefly examine the evidence-base in relation to definitive decisional (e.g. specific interventions designed to facilitate decision making) and other informational supports (e.g. internet, media) in one particular context; the use of decisional support aids amongst people with cancer.

Evidence base for the impact of DA use among the cancer population

Over the past 20 years, there has been a proliferation in research on the use of resources to facilitate communication between the doctor and patient in the cancer setting. This is dominated by research investigating patient outcomes, from a clinical perspective using quantitative methodology. Quantitative studies typically evaluate the use of DAs in relation to decision making about treatment and the impact DA use has on patient anxiety and knowledge about disease and treatment. These studies provide a valuable foundation from which to explore and understand outcomes related to decision making. O'Brien et al. (2009) performed a quantitative systematic review and meta-analysis in the cancer screening, treatment and prevention setting evaluating the use of DAs on two levels:

1. In usual practice.

2. In the clinical utility of one type of DA over another based on the following outcome measures: "patient knowledge", "patient anxiety", "role in decision making" and "decisional conflict".

The review and meta-analysis included 34 randomised controlled trials (RCTs) and compared DA use with a 'wait list' control group, usual practice or with another type of decision aid. Two independent reviewers using established criteria; a combination of the Jadad Scale (Jadad et al. 1996) and Downs and Black Scale (Downs and Black, 1998) assessed the methodological quality. In line with earlier quantitative reviews of RCTs (e.g. Neuman et al. 2007) O'Brien et al. (2009) concluded that use of DA's reduced patient anxiety, enhanced patient knowledge and decision making in comparison to usual practice, particularly in the screening context. They also found that there were too few comparative studies to determine which type of DA was most helpful.

Similarly, a more recent meta-analysis performed by Spiegle et al. (2013) also compared different types of DAs. They included 24 RCTs for review, assessed using the criteria set out by the Cochrane Collaboration and found that there were no significant differences in knowledge, satisfaction, anxiety or decisional conflict scores between patient DAs and alternative forms of decisional support systems. Therefore, these findings suggest that less complex non-specific supportive interventions such as pamphlets maybe all that are necessary to achieve similar outcomes (e.g. reduced anxiety, enhanced decision-making and patient satisfaction) for cancer patients.

An earlier review by Neuman et al. (2007) discussed the theoretical aspects of decision-making contributing to the development of cancer related decision aids and testing their efficacy. The authors also provided a narrative review of RCTs evaluating cancer-related decision aids. They reported that DAs are beneficial in conveying knowledge about treatment, screening and prevention. However, the efficacy of DAs, specifically in facilitating treatment decision making, was less clear.

As identified by the Centre for Reviews and Dissemination (2014), there are several methodological flaws inherent in the earlier studies that prompt one to question the reliability of the results. For example, although O'Brien et al. (2009) searched relevant databases for articles, they did not report on any search terms and how they performed data extraction. Consideration was neither given to unpublished studies or to publication bias. Spiegle et al. (2013) and O'Brien et al. (2009) reported that generally the methodological quality and level of heterogeneity for RCTs included for review was poor.

Several methods have been shown to be effective for improving a patient's absorption of medical information, including the use of information leaflets and interactive computer

programmes. Systematic evaluation of quantitative research has concluded that DAs, when provided, are clinically beneficial in enhancing patient knowledge about treatment, setting realistic patient expectations and overall patient satisfaction in relation to those who experience breast, prostate, lung and colorectal cancer (van der Meulen et al. 2008; Neuman et al. 2007, Lin et al. 2009, O'Brien et al. 2009; Spiegle et al. 2013). It is therefore clear that, although useful, DAs are created with the guidance of medical professionals rather than patients and as such, these outcome measures do not reflect the reality of what people with cancer experience when using DAs.

Clearly, other factors influence how a person with cancer responds to being given medical information. For example, when a patient has been given information about treatment options and associated side effects their level of anxiety may, understandably, become increased rather than decreased (O'Brien et al. 2009). People with cancer may have an alternative set of outcomes that are perceived to be just as, if not more, relevant than the outcomes defined by studies of quantitative research (Neuman et al. 2007). This approach also neglects the fact that cancer patients also use, or may indeed be influenced by, sources of information such as the internet or family members to understand aspects of their disease and treatment.

From a patient's point of view, qualitative studies have proven more useful in exploring how and the type of sources cancer patients use to meet their changing information needs as they experience their illness (Dickerson et al. 2011). In doing so the type of sources and the informational needs of cancer patients can be better understood and thus provide a valuable contribution to our understanding of how DAs and other resources are used thus allowing clinical implications for policy and service design to be considered.

Rationale for systematic review

There are several methodological challenges of quantitative methods when measuring patient use of information aids in the cancer setting. Firstly, the appropriateness of decision making outcomes including; patient satisfaction, knowledge, decisional conflict, and anxiety have been questioned and there is no consensus, to date, on the most adequate instruments with which to measure these domains (Neuman et al. 2007, O'Brien et al. 2009, Lin et al. 2009). Where patient acceptability of DAs has been evaluated this has been through the objective measurement of appointment duration (Lin et al. 2009). Recent

evidence suggests that there is no difference between the use of DAs and other supportive interventions to patient outcome (Spiegle et al. 2013). This suggests that different information aids, aimed at improving treatment decision- making may, have equal bearing on the aforementioned outcome measures.

Reviews of quantitative evidence, which primarily aim to determine the effectiveness of interventions, lack exploration of the patients' perspective. Whilst attempts have been made to provide narrative synthesis (e.g. Neuman et al. 2007, O'Brien et al. 2009), there are currently no reviews that systematically integrate the findings from the available qualitative literature on how patients with cancer use DAs. Qualitative methods may add greater breadth and depth by focusing on the personal experiences of those patients' who use information aids (Ring et al. 2011). In doing so, reviews of qualitative studies may more accurately reflect patients' experience and inform future service design and implementation of DA interventions in clinical practice.

As discussed, the results from clinical outcome studies provide extensive evidence that DAs can improve knowledge in cancer people with cancer. However, there remains a lack of understanding about cancer patients' information needs in the cancer context and how this population attempt to meet their needs through the use of DAs. Given this gap in knowledge, the past few years has seen the emergence of qualitative research which has investigated cancer patients' perspectives on the use of hospital produced DAs and how cancer patients access sources of information outside of this environment (Lacey 2002, Dickerson et al. 2006; 2011, Thygesen 2011; 2012, Balmer 2005, Rozmovits and Ziebland, 2004). There is a need to systematically integrate these findings and develop a more consistent understanding of the topic. Neglecting to do so may result in the failure to gain a deep understanding of patient perspectives and limit our role as reflective researchers.

Neuman et al. (2007), Lin et al. (2009), O'Brien et al. (2009), and Spiegle et al. (2013) have already performed quantitative systematic reviews and meta-analyses evaluating the effectiveness of cancer related DAs in relation to patient anxiety, patient knowledge, decision making and satisfaction. The scope of these earlier reviews is too wide for the present proposed synthesis. This synthesis therefore will aim to add descriptive value to this existing literature by providing an experiential, instinctive enhanced understanding of DA use and explain the diverse results from the aforementioned reviews that will have potentially significant practical implications for transforming

future clinical, research and service developments (Noyes and Popay, 2002).

To the author's knowledge, no previous qualitative systematic review has been conducted relating to patients' experiences of DA use in the cancer setting. The aim of this systematic review is to explore a specific aspect of cancer patients' experience, that is their reflections on using DAs, to see if their experiences could inform clinicians and policy-makers decision making about the implementation of DAs in clinical practice. Decisional support aids are defined as non 'face to face' resources (e.g. written notes/diagrams, pamphlets, audio tapes, videos, internet) and face to face encounters (e.g. nurses, doctors, other members of the MDT, nurse navigators, and involvement of family and friends).

Review Question

How do people with cancer make use of DAs to meet their informational needs?

Review objective

The objectives of this review are:

1. To use meta-ethnography to explore the extent and manner in which cancer patients use decisional support aids, at all stages of diagnosis, treatment and survivorship;

2. To methodologically assess the quality of relevant studies and describe key findings of the qualitative literature in this area;

3. To identify, synthesise and interpret emergent themes from the identified studies and to discuss the implications of these results by performing a systematic review of relevant published studies.

METHODS

Method of search strategy

The EBSCO host was used to search CINAHL, PsychINFO and SocINDEX, and OVID was used to search Medline and Embase databases. The Cochrane Library and Web of

Science were also searched. All searches were completed on 12 April 2013 using the search terms below including the Boolean operator terms "AND" and "OR".

Search terms

The identified search terms were collated from two papers: O'Brien et al. (2009) and van der Meulen et al. (2008), who conducted quantitative meta-analyses of interventions used in the clinical setting to improve recall of medical information in cancer patients. The current systematic review incorporates search terms used by O'Brien et al. (2009) and van der Meulen et al. (2008) as well as those identified following an initial key word search which yielded 479 papers. The abstracts and titles of these were searched and further search terms were used, in addition to the original search items, with a specific focus on qualitative research.

1. Cancer or cancer* or cancer* or oncolog* or neoplas* or tumo?r* or sarcoma* or leuk?emia*

2. patient* or client* or (service adj user*) or inpatient* or outpatient* or sufferer* or victim* or survivor*

3. memor* or remember* or recall* or retention or recollection or understand* or comprehension* or cognition* or attitude* or decision*

4. intervention* or recording* or leaflet* or aid* or communication* or handout* or (prompt adj sheet*) or education* or coaching* or CD* or DVD* or participat* or multi-media* or mp3* or illustration* or pamphlet* or internet or support* or technique* or information*

5. qualitative research

6. 1 AND 2 AND 3 AND 4 AND 5

Studies identified in the electronic search were compared to the inclusion and exclusion criteria in a three-step process: comparing against study title, abstract and full text (Noblit and Hare, 1988). A total of seven studies were identified by the search (see Figure 2 for flowchart of search results and Figure 3 for study details).

Inclusion criteria

This review included:

- Studies that recruited participants diagnosed with cancer;

- Studies investigating the experience or perception of a decision or information aid on decision making about treatments;

- Studies that collected data from outpatient clinics;

- Qualitative studies only (e.g. using ethnographic, naturalistic, interpretive, grounded, phenomenological, subjective, or participant observational principles)

- Publications up to and including 12th April 2013

Exclusion criteria

The review excluded:

- Studies that evaluate the experiences of medical professionals and/or cancer patients and their family members;

- Studies that focussed exclusively on the technicalities of the DA;

- Studies that were not published in English;

- Case studies;

- Studies that collected data from people with a focus on pre-existing communication difficulties (e.g. individuals for whom English was not their first language and those with a learning disability/difficulty);

- Studies that did not capture patient experiences in qualitative form (e.g. used quantitative outcome measures);

- Quantitative or mixed method studies;

- Research oriented toward local quality-improvement initiatives rather than scientific research, evaluation, and publication;

- Book chapters.

Method of quality assessment

There exists considerable debate about the use of assessment criteria to appraise qualitative

research. Unlike the appraisal of quantitative studies, there is little consensus as to the essential criteria for a high quality qualitative study, leading to the development of over 100 quality appraisal tools (Pope et al. 2007). Despite this, many researchers acknowledge the requirement for well-defined approaches for assessing the quality of research (Pope et al. 2007) and a number of different tools and techniques are now available. The use of quality assessment is further complicated by debate concerning when it should be performed. The need for appraisal of studies before the synthesis has been queried (Pope, 2003). For the present review, however, the appraisal process provided a useful introduction because it helped to narrow down studies that did not meet inclusion criteria and develop an overall profile of strengths and weaknesses of each research paper included.

Walsh and Downe (2005) developed a practical guide for assessing the quality of qualitative studies, having reviewed eight previous frameworks for qualitative research. Quality of assessment consisted of 29 items divided between eight essential criteria (i.e. scope and purpose; design; sampling strategy; analysis; interpretation; reflexivity; ethical dimensions; relevance and transferability). Studies were awarded a score of '1' if the criterion was present and '0' if the criterion was absent or if it was not possible to determine a profile of strengths and weaknesses from information given. This framework was used to identify the quality of the studies rather than to exclude those failing to meet a predetermined criterion. Whilst this may be considered a weakness of the chosen methods, meta-ethnography approaches take the view that quality should not be a criterion used to exclude studies, and ought to be given consideration in the descriptive analysis of each study (Sandelowski et al. 2004). To enhance the validity and transparency of the review, all studies were independently analysed by another researcher using the same quality rating scale (Appendix 1.2) and any disagreements were resolved through discussion. Agreement on each of the individual item scores between the 2 raters reached 100%.

Method of synthesis

Synthesising qualitative research is a complex task. There are many ways of synthesising themes and accounts from studies using qualitative methods including, but not confined to, meta-ethnography, grounded formal theory, cross case analysis and meta-study (Pope et al. 2007). Use of such methods is complicated by the fact that there is no single agreed approach. Contrary to quantitative meta-analysis, qualitative meta-synthesis is not about averaging or reducing findings, but rather enlarging the interpretive possibilities, allowing higher order interpretations or general theories to emerge (Sandelowski et al. 2007).

Meta-ethnography was chosen for this review as it was deemed most appropriate for the proposed research question; to obtain new insight and meaning into the use of decisional support aids by cancer patients which have been identified as effective in improving patient knowledge, reducing decisional conflict about available treatments and overall satisfaction by previous reviews and meta-analyses of quantitative research. This approach also allows for the synthesis of research studies that draw upon a variety of qualitative research methods and permits the transformation of individual studies as an expression of each other's terms. This enables direct comparison of qualitative accounts from studies as opposed to seeking solely the degree of commonality among themes (comparative case study) or facilitating reduction of categories (grounded theory) to generate new theories/ideas (Pope et al. 2007). Noblit and Hare (1988) and Atkins et al. (2008) outline seven stages for meta-ethnography (Figure 1). This synthesis will follow these key steps in order to select, critically appraise and synthesise qualitative research studies. The study themes and quality ratings of each paper are outlined in the results section in Figure 3. The researcher has attempted to share as much of their data analysis procedures to enhance the validity of their work by using the analysis framework by Noblit and Hare (1998) and guidelines set out by Britten et al. (2002).

Figure 1. Seven stages of meta-ethnography (redrawn from Noblit and Hare, 1988)

Step	Stage	Description of each stage
Step 1	Getting started	Develop a research question
Step 2	Deciding what is relevant for initial interest	Define focus of synthesis /Locate relevant studies / Make decisions on inclusion criteria / Carry out a quality assessment
Step 3	Read the studies	Become familiar with the detail and content of the studies Extract metaphors and emerging themes
Step 4	Determine how the studies are related	Create a list of themes and metaphors / Juxtaposition of themes Determine how the themes are related / Reduce themes into categories
Step 5	Translate studies into one another	Arrange each study into chronological order / Compare themes from paper 1 with paper 2 and the synthesis of these two papers with paper 3 and so on
Step 6	Synthesising translations	Higher order interpretation to provide a line of argument synthesis
Step 7	Expressing the synthesis	Discussion and write-up of the results Publication

RESULTS

Results of search strategy

The database search yielded 4866 citations, of which, 872 articles were discarded as they were duplicates. The titles of the remaining 3796 were scanned for relevance to the topic. From the title, 234 articles were deemed suitable. Subsequently, the abstracts of these articles were examined, using the inclusion criteria, resulting in the exclusion of a further 223 articles. This left 11 potentially appropriate articles, of which 4 were excluded after reviewing the full text. The reasons were (Appendix 1.1); patients were at risk of breast cancer but had received no diagnosis (Iredale et al. 2008), English was not the first language for one person in the sample (Korber et al. 2011), another study was an abstract/poster for a conference (Shephard et al. 2012). A further study was excluded because it included the views of health professionals as well as patients (McJannet et al. 2003). The reference lists from all included articles were searched manually to ensure the sensitivity of the search, as electronic searches may not identify all relevant qualitative studies (Walsh and Downe, 2005). The same 3-step search mentioned above was performed and did not reveal any further articles that met inclusion criteria. A flow chart detailing this process is provided in Figure 2.

Figure 2. Flow chart of search results

| EBSCO host search (PsychINFO & CINAHL & Behavioural sciences) 1187 | OVID search (Medline & Embase) | Cochrane library search 873 | Web of Science 1248 |

4866 total

3796 following refworks v2.0 de - duplication

| Title review 234 | 3562 excluded |

| Abstract review 34 | 200 excluded |

| Full text review 11 | 4 excluded |

Incuded for review
7
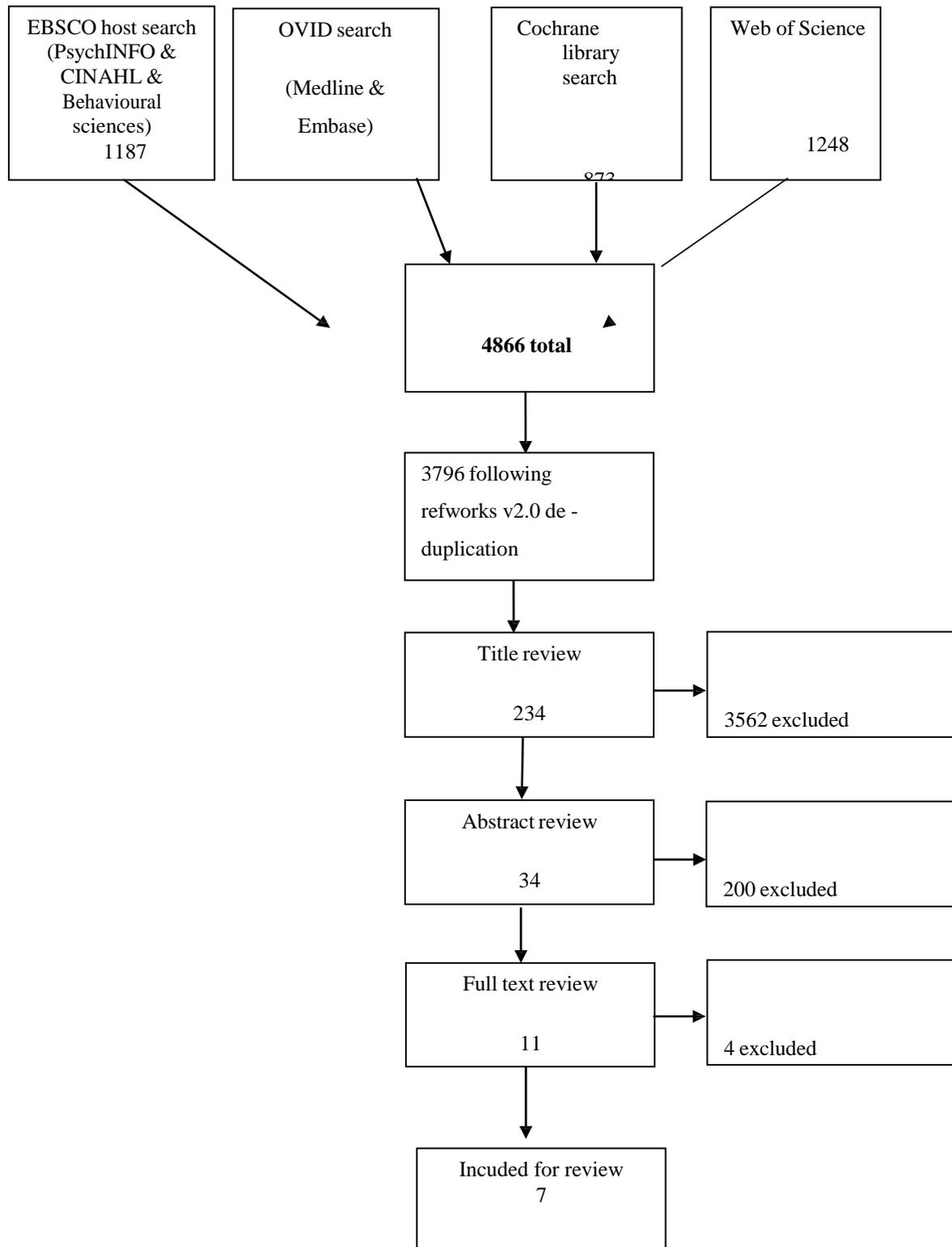
Figure 3: Completed grid methods and concepts

Study	Balmer (2005)	Dickerson et al (2011)	Dickerson et al (2006)	Lacey (2002)	Rozmovits & Ziebland (2004)	* Thygesen et al. (2011)	* Thygesen et al. (2012)
Rating	20/29 = 70%	25/29 = 86%	27/29= 93%	27/29 = 93%	18/29 = 62%	22/29 = 75%	25/29 = 86%
Type of support	All types of media	Internet	Internet	Decisional support aid through nurse	DipEx (interactive website)	Nurse navigator (NN)	NN
Sample	15 (4 males & 11 females) Aged 43-75 Diagnosed with cancer Completed first line treatment	15 males All diagnosed with prostate cancer Aged 47-78	20 patients All female Mean age 52 Variety of cancer diagnoses & stages	12 women Diagnosed and treated for breast cancer Disease free	8 males/females Diagnosed with breast or prostate cancer Age 39-75	5 women Diagnosed with cancer about to undergo surgery Aged 37-76	11 women Diagnosed with cancer about to undergo surgery Aged 32-79
Data collection	Lincoln &Guba's naturalistic enquiry	Hermenuetic analysis	Phenomenology (Colazzi's method)	Thematic methods	Phenomenological hermeneutical	Phenomenology and hermeneutics	Phenomenology and hermeneutics
Setting	Community setting, United Kingdom	Community, support group, north eastern United states	Outpatient setting, 1 to 1, north eastern United States	Home, 1 to 1, North Eastern America	Outpatient setting, focus group, UK	Outpatient setting, Denmark	Outpatient setting, Denmark

 * Thygesen et al. (2011) was part of a larger study Theygesen et al. (2012)

Figure 3. Continued: completed grid methods and concepts

Knowledge	Positive and negative health care professional experiences	Feelings of mistrust with current physician	Personal coping style	Finding nurses were unavailable or uninvolved in initial stages	Consultants not regarded as best sources of information	Individuals whom felt they could use help from NN or bad experiences with health professionals	Individuals who felt they could use help from NN or bad experiences with health professionals
Trust	Some media sources more credible than others. Internet most trustworthy and informative source outside hospital environment.	Concerns about credibility of internet information.	Information sought confirmed with more sites or consultation with support networks/person with medical knowledge	Trusting opinion & advice of physicians about treatment decisions	-	The NN was experienced as trustworthy & forthcoming, who helped them over time	NN experienced as trustworthy, experienced and credible& culturally sensitive
Purpose	"Technical stuff" "Up & coming treatments" "Life stuff" "Other people's stories"	-	Retrieving and filtering information according to personal situation and diagnosis	-	Available 24 hours per day. Approachable. Benefiting from experiences of others without emotional demand.	Patients felt reassured to know they had the same contact over time	-

Value	Contributed to decision making about treatment, information about coping	More knowledgeable about treatment and proactive. Enhanced sense of control and problem solving ability	Enhance decision making about treatment. Provides peace of mind and hope. Self-management and validation of treatment options. Maintaining hope/managing fear.	Nurses support through decisional support deemed most helpful	Allows triangulation of information from other websites and physicians. Sense of peer support	Supplement to loved ones in a period with insecurity and vulnerability. Stable contact with professional knowledge and skills. Increased sense of control and reduced anxiety. Enhanced emotional support	Enhanced knowledge about disease, treatment and psychosocial support
Conclusions/theories	Media was used throughout the experience of living with cancer. This was viewed as a major contributor towards decision making about treatment	Patients selectively used internet information to facilitate provider encounters, monitor reoccurrence, make decisions about treatment and cope with and manage fears.	Internet used to understand illness, manage expectations about coping and verify treatment decisions. "Hearing others stories of survival helped patients manage fears and maintain hope"	" Healthcare providers, particularly nurses, are vital and either positively or negatively viewed". Decision-making process is complex & can cause psychological burden.	Patient demographic profile may influence information seeking. Websites suggested/developed by healthcare staff perceived as more credible than commercial websites.	Nurse navigators viewed as secure base, reliable, knowledgeable and supportive throughout disease trajectory. Healthcare staff ought to be sensitive to endings in context of being viewed as attachment figures.	"Trust or lack of the same in health care professionals/system influenced how patients related to the Nurse navigator" Lack of close family support, culturally sensitive approach may also influence NN use.

Results of quality appraisal

Scope and purpose

The scope and purpose of each study was described with clarity in most studies with researchers making a clear statement of focus for research being, predominantly, to evaluate the lived experiences of cancer patients' who use decision support aids to meet their informational needs. All studies reviewed also demonstrated good sensitivity to context through description of the rationale, aims and review of existing literature in relation to the aims of the individual studies (Lacey 2002, Dickerson et al. 2006; 2011, Thygesen 2011; 2012, Balmer 2005, Rozmovits and Ziebland, 2004).

Design

The design/method of all studies was reported and consistent with the research intent. Three studies demonstrated sensitivity to the epistemological grounding in relation to the rationale for the specific qualitative method used (Balmer, 2005; Dickerson et al. 2006; 2011). Dickerson et al. (2006; 2011) demonstrated particular strength in this area. All researchers provided a description of their method of data collection; either semi-structured interview or focus group and the data collection strategy was apparent and appropriate for all seven studies. Most studies described use of open-ended questions during semi-structured interviews and demonstrated sensitivity to the social/physical and cultural context of data collection (Thygesen et al. 2012; Lacey, 2002; Dickerson et al. 2006; 2011, Balmer 2005).

Sampling strategy

In terms of sampling strategy, all studies used either consecutive, purposive or convenience sampling as their recruitment method appropriate for the aims of the research. Two studies did not give information about non-participation, specifically declining to take part (Rozmovits and Ziebland 2004; Balmer, 2005). The other studies reported reasons for declining participation and dropout (Dickerson et al. 2006; 2011; Thygesen et al. 2011; 2012; Lacey 2002). All studies supplemented this information by providing demographic characteristics of the sample adding to the thickness of description, with one study in particular specifically stating this in the main body of the paper (Thygesen et al. 2012). Thygesen et al. (2011) reported being part of a larger study

(Thygesen et al. 2012). It was unclear from the studies if the samples overlapped.

Analysis

All but one of the studies (Rozmovits and Ziebland, 2004) were explicit about their data analysis methods which included different types of qualitative methods; Collaizzis method, a Phenomenological Hermeneutical approach, a n d constant comparison. Two studies combined the latter approach with Ricoeur's theory of interpretation (Thygesen et al. 2011; 2012). The majority provided detailed descriptions of the qualitative methods used (Dickerson et al. 2006; 2011, Lacey 2002, and Thygesen et al. 2011), demonstrated commitment to the chosen research method through descriptions of data collection, analysis and validation of emerging themes by emailing participants for clarification and agreement about resultant themes (Dickerson et al. 2006; 2011). These studies also reported that data collection continued until the point of saturation (Dickerson et al. 2006; 2011). Two studies described using method triangulation such as diaries and observational information combined with participant interviews (Thygesen et al. 2011; 2012) adding credibility and validity to the analysis process. Lacey (2002) was the only study that reported auditability and provided a description of a decision trail. This was a reflection of the level of variation across the studies within this particular domain. A second researcher was involved in data interpretation in most studies (Rozmovits and Ziebland 2004; Dickerson et al. 2006; 2011; Lacey, 2002). In the absence of a second researcher, however, two papers mentioned that discussions took place with other researchers at various points during data analysis (Thygesen et al. 2012; Balmer, 2005).

Interpretation

The context was described and taken into account as all researchers described use of a specific decision support aid (nurse navigator, internet use, specific website, and family member who was medical professional) in the context of the cancer patients' illness. All of the researchers used interview data to support their interpretations. Rozmovits and Ziebland (2004) and Balmer (2005) were the only two studies that did not explicitly report detailed data analysis, specifically that time was spent dwelling with the data, interrogating it for competing/alternative explanations of phenomena, how agreement on themes were reached and conflicts resolved.

Reflexivity

All but one of the studies (Rozmovits and Ziebland, 2004) demonstrated researcher reflexivity to some extent, reported through description of the analysis process. However, only two studies explicitly reported on "interviewer effects" (Balmer 2005), and the relationship between researcher and participants during fieldwork (Lacey, 2002).

Ethical dimensions

References to ethical dimensions in each study varied. This was a further limitation of Balmer (2005) and Rozmovits and Zibland (2004) as they did not report on any of the ethical dimensions. Lacey (2006) and Dickerson et al. (2011) only made reference to how documentation was managed and did not indicate whether ethical approval had been granted or indeed how confidentiality and anonymity were managed. On the other hand, Thygesen et al. (2011; 2012) and Dickerson et al. (2006) demonstrated sensitivity in all aspects of ethical concerns, including ethical approval, evidencing their dealings with participants, resolving dilemmas and confidentiality and explaining how it was maintained.

Relevance and transferability

Finally, all studies provided a varied amount of evidence of the relevance and transferability of findings. Although Dickerson et al. (2011) and Rozmovits and Ziebland (2004) made reference to theories/literature and outlined directions for research, they did not report limitations/weaknesses of their research studies. Similarly, Balmer (2005) and Thygesen et al. (2011) did not outline any directions for further research.

Results of synthesis

A list of concepts and themes from each of the studies included in this review are displayed in Figure 3. During the stages of meta-ethnography the relationships between themes arising from the different studies were considered. Four overarching concepts emerged across the papers included for synthesis: (i) Knowledge (ii) Trust (iii) Purpose and (iv) Value.

To be explicit about how the themes compared with one another, a visual data display was created to recognise similarities and differences that shaped findings among studies (see row labels in Figure 2). The first four rows of the grid include relevant details of the study

setting and research design. These methodological details are essential contextual information for the synthesis. From the sixth row onwards, each row of the grid represents a key theme. The conclusions in the last row are explanations and theories (Miles and Huberman, 1994).

Second-order interpretations arising from each paper were also established. As a way of preserving the originality in each study, the terms used in the original papers are retained in the grid. Those in quotation marks use the original author(s)' own words; those not in quotation marks are based on the researcher's paraphrasing of the original papers. The grid, therefore, indicates how each theme is encompassed within each study.

Synthesising translations

The themes and associated interpretations were considered from the grid and it was possible to establish how the concepts proposed in one study could be expressed in relation to those used in another study. This involved the use of 'reciprocal translation' that explored themes and concepts of individual studies in relation to one another, attached meanings, and drew inferences from the relationships found between studies.

The use of a matrix (Figure 2) and chart (Figure 3) facilitated systematic comparisons by exploring the themes and identifying common concepts. In order to explore how cancer patients used DAs the concepts of each study were compared one by one with the key theme to establish the extent to which they were similar or different.

In each study the conclusions were identified and highlighted as explanations/interpretations/theories and these findings and themes were then compared with one another within and across studies. This process represented elements of the "line of argument synthesis" component of meta-ethnography, establishing whole themes "amongst a set of parts" (Noblit and Hare, 1988). Four third-order interpretations were formed (Figure 4).

Figure 4: second and third order interpretations

Themes	Second order Interpretations	Third order interpretations

Knowledge	Feelings of fear and perceived lack of contact triggered the search for information beyond the health setting.	If healthcare providers provide psychosocial support from onset, then this would enhance attachment, and faith in healthcare professionals expertise and reduce patients anxiety
Trust	Some media sources more credible than others. Internet most trustworthy and informative source outside hospital environment.	Trustworthy information is defined by cultural sensitivity, accuracy, and information tailored to patient need delivered verbally and/or electronically
Purpose	Patients selectively used internet information to, facilitate provider encounters, monitor reoccurrence, make decisions about treatment, cope with and manage fears.	If delivered in this way, information can be empowering, allowing patients to be active members of their treatment throughout the trajectory of their illness
Value	Enhanced decision making about disease, treatment, quality of life and psychosocial support.	Patients experience an enhanced sense of control, reduced vulnerability and perhaps improved healthcare, adherence to treatment and quality of life.

Summary of themes from the studies reviewed

As Miles and Huberman (1994) propose, line of argument is established through the consideration of each theme and second-order interpretation subsequently. The line of argument, which constitutes the synthesis achieved in this review, is as follows:

There are two types of information sources patients' use: 'face-to-face' contact (e.g. with health care professional) fend non 'face-to-face' contact (e.g. the internet). The use of a decision aid is an example of a patients' need to be proactive and involved in

aspects of his or her healthcare, illness and treatment. The search for information about cancer is predominantly precipitated by the following events: negative interactions with healthcare professionals, lack of support from within existing network of friends and family to crosscheck information given by healthcare professionals and to seek support from other cancer patients. For others a real avoidance of any information related to their illness was apparent as they expressed their shock, uncertainty and fears following diagnosis.

Patients may have felt overwhelmed by the complexity and emotional impact of their illness or the information they received. Individuals may not have taken on board information perceived not to be medically legitimate or reported "switching off" if this occurred, thus inhibiting their ability to understand medical information. From the media, the internet was deemed the most up to date and credible source. However, the patient viewed commercial websites with caution. Information gleaned from the internet was filtered and verified with physicians. Where nurse navigators were used as trusted information aids, they were perceived as close attachment figures. Thus if the patient trusted the source of information they tended to take it on board.

Communication between healthcare providers and cancer patients can be improved if there is trust. Trust is established to the extent to which each source is deemed credible, valid, consistent, culturally sensitive and available from the onset. Lack of trust can give rise to feelings of fear and vulnerability contributing to poor decision making about treatment, symptom management, coping and management of quality of life issues. Using 'face to face' and non 'face to face' information aids, cancer patients can ultimately benefit from the stories of other cancer survivors' sense of empowerment, problem-solving and peer support. This can in turn facilitate encounters with health care professionals and, in particular, validate treatment recommendations.

Detailed quotations related to the themes identified are now described. The process of synthesis drew out the following four key themes for patients using an information aid (i) Knowledge (ii) Trust (iii) Purpose and (iv) Value. By categorising the most prominent elements identified in the synthesis, each theme will be discussed in turn. Quotations from study participants appear in italics, quotations from the authors of the studies do not.

Knowledge

All studies indicated that a patient's information needs were complex and changed over time. Patients reported either feeling "shocked" or "overwhelmed" at diagnosis and

this was also noted as a crucial point at which patients then began seeking information. Most studies described patients' as feeling the emotional impact of their cancer diagnosis and their feelings of vulnerability superseding the need for the use of information support aids. In contrast to this, Dickerson et al. (2006) reported that many 'internet savvy' patients used the internet to gain an understanding of disease and to research the possibilities for cancer treatment once a cancer diagnosis was suspected.

Rozmovits and Ziebland (2004) note that immediately after diagnosis many were too shocked to take in information but, within a few days, their need for information evolved into a sense of urgency for treatment. One participant in their study describes their experience:

"I went right head–on into it, to get it done. To get it taken care of, I mean, I was going to go for a second opinion, but it was there. You know as someone said, "why don't you go for a second opinion", but when I went back and she showed us the pathology reports, the cancer is there" (Unknown, Rozmovits and Ziebland 2004).

All studies reported that participants were not completely satisfied with the support that professionals provided for them prior to cancer treatment (Balmer, 2005; Lacey, 2002; Rozmovits and Ziebland 2004; Dickerson et al. 2006, 2011; Thygesen et al. 2011, 2012). Experiencing a sense of uncertainty, patients subsequently responded by seeking information from a variety of sources including family members, friends, physicians, support groups and various forms of media. The internet was most commonly used for various purposes including understanding the disease, treatment possibilities, and decision-making.

"You get a lot of information verbally and you remember most of it, which I did, but when I went home I realised I didn't fully understand the implications...it was just a lot of information and a lot of words and I didn't really know what it meant. For example, they say "we found abnormal cells but we don't know if its invasive, come back on Tuesday and you go away...and you think I don't know what that means... you get a lot of verbal information but it's very hard to take in at the time, especially if you are on your own" (Breast cancer patient. Rozmovtis and Ziebland, 2004).

This quote indicates that whilst the patient expects consultants to provide adequate information this was not always achieved. Lack of time, preference for

particular forms of treatment and poor communication skills were common problems (Thygesen et al. 2011). Arguably, these factors could have collectively contributed to a patient's distress and sense of vulnerability, to mistrust in healthcare professionals and so increased the difficulty of coping with a serious illness.

Lacey's (2002) study emphasised the inconsistencies in patient experiences of health professions in terms of their communication skills and expert knowledge. While some participants felt safe and secure with their consultant, others felt nervous:

"I just wished that they would give me an opinion ...but they didn't and this made me a little nervous" (Unknown, Lacey 2002).

Balmer's (2005) study reported that the majority of participants expressed faith in the information they had received from health professionals, though a hint of pessimism was also present in their experiences. Some patients conveyed a sense of obligation to believe and rely on health professionals as though information from other sources might lead to confusion and doubt.

"I just decided that the people here are the experts. I've got to trust them because if I don't what else can I do? There's no point in taking yourself down other avenues if you've elected to do what the consultants told you. You don't want to read too much in case you start going
...mmmmm" (Balmer, 2005).

Participants described unhelpful experiences concerning information given by health care professionals and this caused them to rely more heavily on other sources of media-produced information.

This was evident from the quotation below:

"It's complex, the outcomes of the treatment are the same, it is what you go through to get there." (Unknown, Dickerson et al. 2011)

Patients generally expected health care professionals to give information in a way that they could understand. However, in reality the results from studies showed that

physicians were not always viewed as the ones with all the expertise and knowledge. This often resulted in the patient seeking information from elsewhere as well as from the primary specialist involved in their care.

Trust

In all studies the patients' reported that they sought information about their cancer throughout the course of the disease, from the point of diagnosis to treatment and beyond (Lacey, 2002; Rozmovits and Ziebland, 2004; Dickerson et al. 2006; 2011, Thygesen et al. 2011; 2012). They explained that, once they were over the initial shock of the diagnosis, they tried to acquire as much information as possible from a range of different sources. These sources included medical professionals (most often), followed by the internet; nurse navigators; as well as print (e.g. pamphlets, leaflets, books) and television media to aid their decision making as well as coping/symptom management over the disease trajectory. It was apparent that the patients trusted and needed physicians to make the decisions for them (Lacey, 2002; Dickerson et al. 2006, 2011).

"Well, the physician gave me all the possibilities of what it possibly could be and if this is cancer, how he would recommend that we would take care of it. He just made me feel really comfortable" (Unknown, Dickerson et al. 2006).

Thygesen et al. (2012) also identified that the use of a nurse navigator decision aid depended on the nature of the patient's hospital experiences. For example, negative hospital experiences were disclosed to the nurse navigator. Prior to meeting the nurse navigator, they had built up "guarded trust" in health care professionals and the hospital system as a whole.

"Doctors come and go as they see fit...they come and say their bit and they leave again...as far as turn their back on you at the same time, I mean ...really!" (Unknown, Thygesen et al. 2012).

Some media sources were deemed better and more credible than others. The Internet was consistently seen as the most trustworthy source and the information it contained was always considered valid and valuable.

"You can't always believe what's in the newspapers: the media hierarchy. (Unknown, Balmer, 2005)

Individuals who had feelings of mistrust with their physicians sought information from other sources or they switched from consultants, who gave them the "impression of them being pushed out of the door". In terms of the internet, patients related that although they used the internet they tended not to take the information as absolute truth but with a "grain of truth" (Dickerson et al. 2006; 2011)

Purpose

Most of the studies reported on the nature and purpose of information patients sought from sources other than their primary medical contact (Lacey, 2002, Rozmovits and Ziebland, 2004, Dickerson et al. 2006; 2011, Thygesen et al. 2011; 2012). Approximately half of the studies cited internet use as the most widely used form of media accessed by patients, beyond initial advice from medical professionals (Ziebland and Rozovits, 2004; Balmer, 2005; Dickerson et al. 2006; 2011).

Balmer's (2005) study defined information sought by patients into two main categories 1) "technical stuff" and 2) "life stuff". In broad terms, two other studies also defined participants as seeking information in this way (Rozmovits and Ziebland, 2004; Dickerson et al. 2006; 2011). Researching medical information and difficulties in understanding medical terms also triggered internet searches as reported by one patient in Balmer's (2005) study:

"When they first told me I had this disease, they said there was no cure. We went on the computer and we found out that wasn't necessarily the case. Here was...something more that could be done...there was more hope for me. They were doing good things with bone marrow transplant...(my daughter) got ...updated information...that made it really a lot better for us, even though it was risky." (Unknown, Dickerson et al. 2011).

The same study also reported the cautious way in which patients processed information from the internet:

"Sometimes I am afraid to get on the (internet)...if it's going to happen to me. I don't know

if I really want to know that, although I know that these are things that are going to happen and I suppose I should be prepared." (Unknown, Dickerson et al. 2011).

Patients typically used the internet for learning about *"life stuff"* as opposed to *"technical stuff"*. *"Life stuff"* included coping with day-to-day reality of living with cancer, practical and emotional support (Dickerson et al. 2006; Rozmovits and Ziebland 2004). Patients related well to "other people's stories" about their cancer experience and found it very useful (Balmer 2005).

Patients reported mainly positive experiences, as one participant describes:

"Going to the internet and seeing other people having the same ideas and problems were a big help. Reassuring like nothing else did" (Unknown, Dickerson et al. 2011)

Therefore, the content of information provided by medical professionals and the level of familial support influenced the extent to which patients accessed information beyond the medical health setting. These positive or negative experiences influenced a patient's beliefs about treatment success which in turn had an impact on their feelings of trust and sense of safety and attachment with health professionals. Qualities such as good communication, information giving and support were all positively viewed and the Nurse Navigator (NN) was often used to explain the medical information that patients were given. Staff responses towards patients, including lack of information pre and/or immediately post diagnosis, contribute to maintaining hope and a sense of vulnerability prior to treatment.

Value

Participants tended to use this information to both facilitate encounters with their providers as well as monitor their own health status for the cancer reappearing. For some patients, the more knowledge they held about their condition, the more proactive they were when dealing with the healthcare professional involved in their care in relation to their treatment. 'The men used this increase in knowledge as a currency to enhance their own sense of control and power in the patient provider interactions' (Dickerson et al. 2011).

'While they asked for clarification and came prepared with a list of questions they often

used their physicians as the end point for verification of the decision' (Dickerson et al. 2011).

If the patient perceived web information as credible and usable, they then shared this with trust in the physician which ultimately influenced final decision making. The majority of cancer patients collated internet information with 'a grain of salt' but appreciated being able to access potentially distressing information, without the emotional demand (Rozmovits and Ziebland, 2004).

Individuals who had received help from the NN experienced a mutual connection and they quickly built up confidence in the NN (Thygesen et al. 2006; 2012). However, those that did not seek help from the NN had close relations with a healthcare worker who helped them in the same areas as the NN (Thygesen, 2012).

"I have not used the NN because I have my children (one of whom is a healthcare professional and) she has followed me through this (at discharge)" (Unknown, Thygesen et al. 2006; 2012).

In Rozmovits's and Ziebland (2004) study, patients positively described their use of the DipEx website from which they could select and view the life and illness profiles of cancer patients and felt that this greatly reduced feelings of fear and isolation during their illness. In addition to this, the majority of participants in this study expressed that this would have encouraged them to become more active decision makers about treatment. However, the lead researcher and interviewer of this particular study was also involved in the development of the website which may have resulted in researcher bias and the favourable reporting of results.

The internet was accessed to seek information about specific types of cancer and validate treatment recommendations. Sometimes this enhanced confidence but other times created fear. 'Internet savvy' patients explained how they searched for accredited sites, verifying the information with other websites and had the most confidence in sites which were affiliated with health service organisations (Dickerson et al. 2011).

"There was one lady with non-Hodgkin's lymphoma and she was writing a sort of celebration of her life; how she got through it. She lost her hair but its growing

34

back and she was talking about going on holiday. Yes that was interesting. In fact, quite inspiring" (Unknown, Balmer 2005).

On completion of treatment participants differed in the amount of information they required. A minority felt it was more helpful to move forward and 'leave it all behind'. However, most felt they would always have an interest and continue to seek information (Rozmovits and Ziebland, 2004; Thygesen et al. 2011; Dickerson et al. 2006; 2011) about coping with the day-to-day reality of living with cancer or the possibility of recurrence, including practical and emotional support.

DISCUSSION

This systematic review has used meta-ethnography to obtain new insight and meaning into how patients use decision aids (DAs) within the cancer setting. The aim has been to enable a better understanding of earlier quantitative reviews that identified DAs as effective in reducing anxiety, decisional conflict and improving knowledge about their illness and treatment**.** The methods of synthesis used encompassed all of the types of information aids cited in previous quantitative investigations of patient DA use: pamphlets, internet websites, nurse navigators, and CDs. Four major concepts have been identified: (i) Knowledge (ii) Trust (iii) Purpose (iv) Value. The themes were closely linked objectively and subjectively, as reported by the patients themselves.

Main Findings

Similar to the present discussion of trust, the literature reflects that patients have personal trust (e.g. specific health care professional), and more generally, social trust in healthcare systems and practices (Hunter and Maunder, 2001). When patients feel vulnerable, they are likely to seek closeness and attachment to a person they consider reliable and safe to help (Bowlby, 2008). The health professional may become a trusted person to the patient given their need for closeness and reassurance (Salmon and Young, 2009). In line with quantitative reviews (O'Brien et al. 2009) DAs, appear to have enhanced patients' sense of empowerment, problem-solving and peer support, as well as facilitating decision-making about treatment and coping with the disease. The present review distinguishes that, regardless of type, information aids perceived as trustworthy and

tailored to patient need are most beneficial to patients. More specifically, this review demonstrates that the cancer patient can benefit from other cancer patients' stories based on their coping with the illness. Information is gained predominantly from the clinician involved in their care and supplemented by the internet being used to facilitate consultations, research signs of cancer recurring and validate treatment decisions. This has in turn influenced patients' emotional reactions, resulting in a reduction of fear and isolation and enhanced coping with the disease.

Figure 5: Emergent themes

| Intervention to facilitate cancer patients decision making about treatment | Why are patients seeking to advance their medical **knowledge** alongside their routine care? | What sources of information do patients **trust**/use? | What type of information is sought, and what **purpose** does this serve? | How does this information meet the needs of cancer patients, what is that they **value**? |

Across the cancer journey

Methodological challenges

The requirement of identifying and evaluating methodological difficulties to challenge the findings of a study remains a significant issue in the assessment of qualitative research (Guba and Lincoln, 1994). As in quantitative research, the robustness of findings may depend on the specific design or method chosen (Noyes et al. 2011).

The methodological evaluation suggested a number of strengths and limitations within the literature. The majority of the studies demonstrated strengths in methodology, particularly in scope and purpose, design, data collection methods and sampling strategy which were reported by all researchers. Not all studies were explicit about analysis and not all described the process of data saturation. Few studies mentioned that findings were validated and whether themes were crosschecked. It became apparent that the themes identified by the authors were not definitive or easily separable. Whilst authors used different labels to identify similar themes, the content did not necessarily differ. Only one study explicitly reported auditability of the research process and findings. This was surprising since it is the actual audit trail, provided by researchers, that allows for an in-depth evaluation of a study (Hannes, 2011). All studies used interview data to support their interpretations.

The majority of studies described the relevance of their findings in the context of literature and reported directions for future research and clinical implications. However, some failed to report weaknesses or limitations. Researcher reflexivity was also another aspect that was poorly demonstrated, if at all, by the studies included for review. Only one study reported the possible influence of the interviewer during the data collection process. In relation to ethical standards, some failed to mention any details regarding ethical approval, explanation of research to participants, procedure for informed consent or ensuring confidentiality.

Overall, there is significant debate in the literature regarding whether or not concepts such as validity and reliability are applicable to qualitative research and if so, how they should be evaluated. Some researchers have stated that qualitative research should establish validity, reliability and objectivity. Other authors argue for a modification of these concepts to provide a better fit in the qualitative research design (Guba and Lincoln, 1994).

Strengths and limitations of this review

Strengths

The author is not aware of any other syntheses of qualitative literature investigating patients' perceptions of DA use in the cancer setting. Qualitative meta-synthesis is still an emergent field with little consensus on a single way of doing it. Following the principle set out by Miles and Huberman (1994) of establishing a clear research question,

this study has sought to present findings encompassing transparency and explicitness. To ensure robustness, the articles were independently read and coded. The methods of the study were also explicitly described and presented in written and diagrammatic form. Reaching clarity about how each theme translated into another and how higher order interpretations were formed was also attempted. The researcher also attempted to ensure that themes were grounded in the papers' findings by systematically returning to the text of the original articles throughout the analysis process.

Limitations

There are a number of limitations to the current review which should be addressed. Only published studies, from this small and emerging field, were included in the current review and research papers were limited by the search strategy used. Therefore, there may be a publication bias, meaning other relevant studies may have been excluded. Within the literature, a bias was evident with regard to DA experiences of patients diagnosed with breast or prostate cancer as opposed to other forms of cancer. This may be because use of DAs has been more frequently investigated in prostate and breast cancer patients than in any other form of cancer. However, this may also reflect the fact that breast and prostate cancer are among the most frequently diagnosed cancers in the world (World Health Organisation, 2014). The views of those who did not wish to participate were also not recorded and this possibly resulted in a group of patients who are underrepresented. Arguably, the results of the systematic review may only represent the information needs of groups that are willing to participate and they are predominantly breast and prostate cancer patients. The methodology of each study was assessed and many of those considered for review demonstrated methodological weaknesses. The findings of these studies were not excluded based on this but still synthesised in the context of the methods used by each study. Finally, the validity of the meta-synthesis could have been improved by returning the interpretations to the original authors and researchers involved in the research studies.

Reflexivity

Although the current review captured the main themes from the studies, the review was predominantly subjective. Therefore, the values and beliefs of the reviewer may have influenced her interpretation of themes within the synthesis (Pope et al. 2007). However, the reviewer also believes the findings were strengthened by her professional

background. The field supervisor is a consultant clinical psychologist at a national cancer centre. The academic supervisor has a specialist research interest in communication among health care professionals and their patients, within the health care setting. Discussions with supervisors encouraged the researcher to think conceptually allowing patterns and themes to emerge and thus permitting interpretations of data. A possible strength of the review is that it included samples of participants from various outpatient settings and monitored the changing information needs of participants over the development of the disease/treatment.

Clinical implications and directions for future research

This synthesis emphasises the key role that health care professionals can play through providing cancer patients with information or decision aids that embellish trust and are sensitive to their individual needs. DAs provided in this way can influence an individual's ability to facilitate encounters with healthcare providers in various ways. For example, the cancer patient may be able to better monitor their own health status, validate or make decisions about their treatment as well as cope with and manage the disease. It is hoped that this review will provide researchers and clinicians with an understanding and context, informed uniquely by the patients' subjective experiences and reflections, about why and how they use information aids in clinical practice.

For health care professionals, this review suggests that patients' wish to have the option to be actively involved in treatment and care decisions. It would be of importance, therefore, for services firstly to seek out the individual information preferences of their patients as endorsed by policy. For example, clinicians can explore with the patient the level of support within their family system and other sources of information used to supplement the information given to them. This may subsequently lead to onward referral to general sources of information, e.g. NHS based websites, or more tailored approaches, e.g. nurse specialist or navigator, to supplement the information given to them at consultations. This review has shown that cancer patients relate particularly well to the personal stories of survivors', regardless of the type of DA. This is an important finding that can be incorporated into the design of any intervention and content of interaction aimed to facilitate the doctor patient encounter.

The themes from this review have elucidated that trust in individual clinicians and sources of information remains paramount when supporting cancer patients with decision aids. This can positively influence patients' sense of empowerment, reduce anxiety levels and

enhance decision making about treatment. The overlapping of themes reflects the importance of checking on the evolving information needs of cancer patients throughout the journey of their cancer, involving family members and tailoring information to meet the needs of individual patients. For researchers, the review identifies areas for future research. Firstly, the review emphasises the need for further qualitative research evaluating DA use among cancer patients in the NHS setting, where all but two studies were carried out in the United Kingdom (e.g. Balmer, 2005; Rozmovits and Ziebland, 2011).

A focus on developing information aids that are tailored to individual consultation content and evaluation of the impact of this among patients in different cancer care settings such as palliative care is also required (O'Brien et al. 2009). Surprisingly, given the growing availability of charity-based support for cancer patients, the narratives of cancer patients did not reflect use of support from cancer charities in relation to any aspect of living with cancer. Future research could consider the impact of other forms of support including charities as well as the media on patients' experiences in relation to illness management. Exploring the impact of particular components of DAs, in relation to one another, such as the usefulness of patient stories in coping with cancer in comparison to advice on practical support on living with cancer as provided by healthcare organisations, might also be considered for future research.

Conclusions

This meta-synthesis implies that the search for information about cancer out with the medical setting, whether recommended by clinicians or not, can be precipitated by negative interactions with healthcare professionals or by lack of support from within their existing network of friends and family. It also recognises that from the patient's perspective, optimal healthcare can only succeed if there is trust in the healthcare provider and the information given. In countries such as Denmark, the United States of America and Sweden private health care insurance is required which may influence the level of care a patient with cancer experiences. Therefore, it cannot be assumed that information interventions alone will be deemed credible, valid, consistent, culturally sensitive and available from the onset. If health care professionals in the cancer setting can identify an individual patients information needs during clinic appointments, then they can also signpost them to receive the relevant support such as internet websites, nurse navigators or specialists that can provide information tailored, as much as possible, to individual patient need.

By understanding the subjective experiences of cancer patients who use DAs, clinicians can identify why and how patients make use of DAs to meet their unique informational needs. They can thereby provide tailored DAs that have been shown to facilitate encounters with doctors, monitor their health status for recurrence, reduce fear and isolation, validate treatment decisions and enhance coping with the disease. Whilst the purpose of this systematic review was to supplement existing quantitative reviews with patients' perspectives, (e.g. O'Brien et al., 2009) and gather research knowledge concerning the topic regardless of the strength of the evidence, the methodological shortcomings of studies included for review perhaps limited the strength of the findings. In terms of service redesign and informing policy, researchers might be able to improve the methodological strength of findings by employing a model to assess the trustworthiness of findings (Guba and Lincoln, 1994). This would involve measures such as an audit trail, peer examination, reflexivity and triangulation. Finally, the researcher acknowledges the considerable cost implications attached to developing DAs tailored to a cancer patient's needs, in terms of coordinating, developing and distributing DAs affiliated to the health organisations that patients attend. However, it is hoped that this review can provide credible and original evidence required to justify the allocation of resources to the development of DAs or alterations to the content of service delivery required to meet the evolving needs of cancer patients.

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CHAPTER TWO:

Major Research Project

Methodological challenges of developing a tool to measure patient recall and understanding from a Haematopoietic Stem Cell Transplantation (HSCT) consultation

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ABSTRACT

Background: In comparison to other medical appointments, consultations regarding haematopoietic stem cell transplant (HSCT) tend to be emotional and longer due to the high volume and content of information exchanged between the patient and consultant. HSCT offers the potential to cure the cancer but also carries a multitude of life-threatening side effects. Existing research has shown that patients immediately forget the majority of information they receive in medical consultations thus resulting in misunderstandings about treatment, adjustments and about coping post transplant. Despite this, no previous research has evaluated cancer patients' level of recall and understanding considering the volume of information they receive from doctors during consultation for HSCT.

Aim: To create, within a haemato-oncology setting, a coding framework capable of evaluating the interaction between the patient and doctor in the HSCT consultation.

Methods: The medical consultations of five HSCT patients who were eligible for HSCT were recorded and these patients subsequently completed semi-structured interviews. Transcripts were analysed using directed content analysis. A recall and understanding information template (RUIT) with an associated coding framework was developed and piloted.

Results: The procedures undertaken in developing the RUIT demonstrate strong inter-rater reliability and content validity. Further testing, through piloting the instrument, indicated that the RUIT coding system has strong inter-rater agreement. However, disparity in the classification of some categories was also revealed. Cancer patient's viewed the consultation as informative but also felt that both the content and volume of information they received were difficult to process.

Conclusions: This study is the first qualitative investigation of cancer patients' recall and understanding of content from a HSCT consultation through the unique development of a coding framework. Future use of the RUIT in clinical practice and recommendations for further research are discussed in relation to the relevant literature.

Key words: Haematopoietic, recall, understanding, consultation, content analysis

Introduction

Cancer patients' information needs

The World Health Organisation (2014) reports that cancer is becoming a leading cause of death globally. Prevalence is increasing in both solid tumours and blood cancers due to a combination of improvements in prognosis and screening techniques, as well as to an increase in incidence (Cancer Care in Scotland, 2014). Solid tumours consist of an abnormal mass of cells that typically stem from different tissue types such as the liver, colon, breast, or lung. In contrast, haematological malignancies are cancer types affecting the blood, bone marrow and lymph nodes. Given the rise in detection and treatment of cancer, researchers are seeking to increase their understanding of the nature and extent of the doctor-patient relationship in the cancer setting (Carlson et al. 2005). Consequently, more recently, there has been an increased focus on investigating cancer patients' information needs.

The communication process is the vehicle through which a trusting relationship with the patient can be established by providing cancer related information sensitively and responding to the psychosocial needs of the patient (Hack et al. 2005, Brundage 2010; Fagerlind et al. 2012). The essential criteria for successful interactions between health care providers and their patients are that the amount of information given is *"adequate, and that it is understood, believed, remembered and hopefully acted upon"* (Fallowfield and Jenkins, 1999 pp. 34). Communication regarding disease status should embrace discussion about tests, available treatments and information about both physical and psychological symptoms. There is often a significant mismatch between doctor and patient understanding of prognosis, suggesting poor communication of this aspect of disease status which can lead to over estimation of life expectancy (Butow, 2005; Rodriguez et al. 2010).

It has also been suggested that patients who misunderstand aspects of their consultation are less satisfied overall with the service they receive. This, in turn, can result in poor decision making about cancer treatment, misinterpretation of consent procedures, increased anxiety, poor adherence to treatment adjustment and difficulties coping with treatment side effects (Hagerty et al. 2005a). Individuals with cancer, therefore do not easily understand cancer and its treatment and efforts ought to be made to detect and clarify misunderstandings that subsequently mislead the patient.

Debate has taken place regarding the most appropriate research methods to assess communication within cancer consultations. Despite this, the need of cancer patients to receive satisfactory communication is poorly understood. For example, studies that employ quantitative methods use questionnaires or surveys developed by researchers that are not based on cancer patients' experiences with clinicians (Carlson et al. 2005). Information about prognosis and the psychosocial aspects of quality of life have been omitted during informed consent trials and evaluations of consultations with patients who have been diagnosed with advanced cancer (Rodriguez et al. 2010; Jenkins et al. 2011). There is also a lack of clear agreement on guidelines to clinicians on how to provide information about cure and survival to cancer patients (Hagerty et al. 2005b). Collectively, these factors may contribute to a patient misunderstanding information from a cancer consultation. In particular, little is known about communication with patients suffering from haematological malignancies, despite significant differences between the outlook and treatment of haematological malignancies and other tumors (Rood et al. 2014).

Current communication research in the cancer setting

Carlson et al. (2005) comprehensively reviewed research methods and outcomes most commonly used to investigate the doctor patient interaction in the cancer setting. They found that many variables have been identified and their effects investigated. They are: the interpersonal skills of the doctor (Hack et al. 2005; Jenkins et. al 2011), patient satisfaction, compliance (adherence to treatment), knowledge, recall, understanding, coping, status, psychological state (e.g. anxious or depressed) (Ong et al. 2000) overall quality of life (Fagerlind et al. 2008) shared decision making (Thorne et al. 2010), and prognosis (Hagerty et al. 2005b). The authors used the conceptual framework of Feldman-Stewart et al. (2005) to characterise communication exchange within the cancer setting through five inter-related dimensions which they propose can enhance or hinder successful communication (Figure 1). The authors concluded by recommending that future methods used to evaluate doctor patient communication in the cancer setting ought to include data collected through patient interviews, as well as objective measures such as video and audio recording.

Figure 1. Feldman-Stewart et al.'s (2005) conceptual framework for patient-professional communication

Source: Int J Qual Health Care © 2012 Oxford University Press
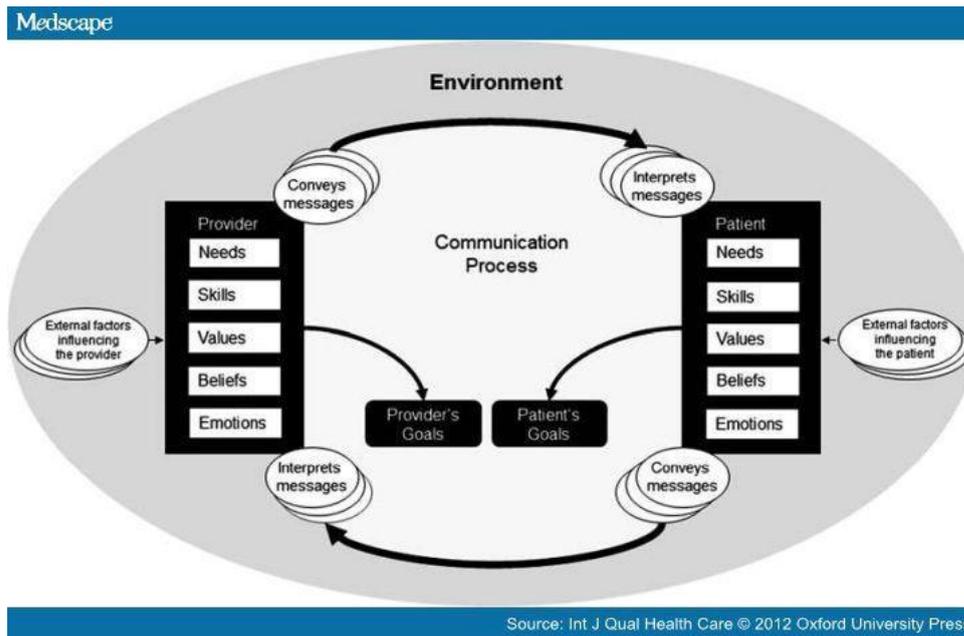
- The first dimension focuses on the interaction between each person's communication goals and their perceived outcomes. Goals are defined, as an expression of each person's needs, with the aim that they should be met.

- The second dimension focuses on five key characteristics intrinsic to the patient and doctor, including; skills, needs, values, beliefs, and emotions that enable the professional and the patient to work together towards their goals.

- Other components of the framework encompass the environment and external factors used to represent communication that occurs in the cancer setting.

- The communication process, the final element of the framework (and focus of this thesis) involves conveying and receiving messages. These include verbal messages (e.g. discussion of the disease, prognosis, and quality of life) as well as non-verbal behaviours (e.g. body language and facial expressions) that may influence what may or may not be understood and recalled by the patient.

Communication research in the haemato-oncology setting

The most substantial review of the information preferences of individuals' with a haematological malignancy is provided by Rood et al. (2014). The authors reviewed 14 studies with a total of 1938 participants with various diagnoses of a haematological malignancy. They included both quantitative and qualitative studies that investigated the informational needs of this population, the sources of information used and satisfaction with the information received by their doctors (Yogaparan et al. 2009; Mohamedali

52

et al. 2010; Parry et al. 2011). The review suggested that almost all patients' wanted basic information about their diagnosis, specifically treatment related information rather than psychosocial information. The need for detailed information was varied, with individuals preferring basic information on treatment. Where HSCT was an option, general details were valued over indepth information. Rood et al. (2014) cited a number of papers which showed consistency between doctors and patients in relation to the importance and need for medical information. However, this was not demonstrated in relation to the need for psychosocial information.

Research has shown that the amount of information given during cancer care consultations can be difficult to process and without clear content and structure (Carlsson et al. 2013) can potentially give rise to poor recall and understanding of information (Fagerlind et al. 2008; Grulke and Bailer 2010, Rodriguez et al. 2010). Patients' who consider they have not received enough information or misunderstand the information they have received can be left with increased feelings of uncertainty, anxiety and confusion. This will result in their needs not being fully met (Hacking et al. 2013; Fagerlind et al. 2012). In line with the findings, from these earlier studies the Rood et al. (2014) concluded that although there is a considerable knowledge on what constitutes good communication between doctors and patients' with haematological malignancies, studies focusing on what comprises doctor-patient communication in the HSCT consultation is limited, indicating that further research is needed.

Friis et al. (2003) described the information needs and information seeking behaviour from the perspective of patients' with acute myeloid leukemia. The authors used qualitative ethnography, interviewing each of the 21 participants at two separate time points; firstly at the time of diagnosis and again 2 to 5 months post diagnosis. Most patients demonstrated poorer recall of information immediately after diagnosis. The only information they did recall related to the diagnosis and their emotional state. In contrast to the results of earlier studies, the participants under investigation did not seek detailed medical knowledge about their illness (e.g. prognosis) and treatment. Participants attached more importance to information about problems affecting their everyday life and how other persons had coped with their illness.

Grulke and Bailer (2010) investigated the level of agreement between patients' and doctors' estimations of prognoses prior to HSCT, using quantitative methodology. Patients and doctors were invited to estimate the patients' chances of cure on a Lickert scale

as well as indicate psychological state and coping on self report questionnaires. The agreement between doctor and patient prognosis estimates was found to be poor. Doctors' ratings were positively correlated with actual survival but patients' ratings were not. In terms of psychological state, the authors' found that patients' evaluation of their prognoses was highly correlated with their distress. They hypothesised that psychological processes such as denial or repression are most likely to impact on concordance. However, the authors' failed to provide specific descriptions in relation to the categories and rating system used. Validity can be compromised if the content of a questionnaire is not based on previous qualitative research or if methodology is not easily replicable.

Alexander et al. (2012) evaluated 236 initial sub-specialty consultations between haemato– oncologists. They observed that haemato–oncologists underuse many mechanisms that may enhance communication and the usefulness of the consultation. Typically, the consultation tends to cover a preference for an information and decision-making role, and checking patients' understanding of presented information. Haemato-oncologists discuss quantitative estimates of mortality and cure resulting in highly emotionally driven content with patients they are meeting for the first time. Most commonly information about the purpose of the visit and patients' knowledge about their disease were discussed. Other elements such as a patient's preference for their role in decision-making, preferences for information, or understanding of presented information were also discussed. Treatment recommendations were provided in 97% of the consultations and unambiguous presentations of prognosis occurred in 81% of the consultations. They concluded that by evaluating the information patients receive from the consultation, doctors can tailor the amount and content of information they share with them.

Whilst this is the only study that has set out to characterize the content of the HSCT consultation, it has also provided a useful basis for the present investigation of haematological cancer patients' consultations with their doctors and an indication of the methods required to measure patient recall in this specialist consultation. On the other hand, the study lacks transparency of methods, by failing to make explicit the type of qualitative analysis used.

Assessment of patient recall and understanding of information from cancer consultations

Patient recall of cancer treatment consultations has previously been defined and

measured empirically (Fallowfield and Jenkins 1999; Carlson et al. 2005; Jenkins et al. 2009). Although the research literature fails to provide a clear operational definition of patient understanding of cancer treatment, the concept has been measured (Jenkins et al. 2008). Assessment to improve the communication process will help guide development of interventions that may enhance reaction to treatment related difficulties.

Jansen et al. (2008) investigated older cancer patients' recall of information after patient education, preceding chemotherapy. Jansen and colleagues devised a recall questionnaire which consisted of multiple choice questions related to information about treatment and recommendations using a combination of multiple choice and open-ended questions. The recall questionnaire was a combination of a chemotherapy guide and coded pilot vidoes, which provided the basis for potential topics that could be discussed. Recall was subsequently compared to the actual communication in the video recordings of the consultation.

Results from Jansen et al's. (2008) study showed very low recall scores that the authors partly attributed to the scoring system used. The observation checklist used covered the specific items of the consultation very precisely and a one on one comparison was made between the items presented (using videotapes of the consultation) and recalled. At no point were items prioritised to be of greater importance from the doctor or patients perspective. Recall was measured solely using a recall questionnaire and recall was not probed. Should such a methodology be used to test recall, it will increase the observed recall rate, in comparison to what the authors found using the questionnaire alone.

Jenkins et al. (2011) demonstrated that misconceptions could arise between patients and doctors during the informed consent processes for clinical drug trials in the cancer setting. Consultants completed questionnaires indicating areas they felt they had discussed and researchers performed semi-structured interviews with patients examining their recall and understanding. Independent researchers coded the consultations, identifying discussion of key information areas. Results showed that information was either missing or had been explained but was interpreted incorrectly by patients. They found that discussion of prognosis andpatient understanding about supportive care were frequently omitted, with patients and coders significantly more likely to agree that consultants had not discussed the topic.

Developing methodology to measure communication in the cancer setting

In developing the methods for this study, it was useful to consider the work of past researchers, particularly Roter (1987), who was instrumental in developing scales for the measurement of communication in the health care setting. Roter (1987) devised a coding and classification system to enable researchers to study the content of doctor-patient encounters.

Roter and Larson (2001) proposed that before researching doctor-patient communication, we must ask ourselves why particular communication variables merit measurement and where the variables fit in a broader conceptual and theoretical framework. Roter and Larson (2001) identified a weakness as '*the relative absence of theoretical focus to guide investigators in making basic judgments regarding what to measure, when, and why. This deficit has contributed to the largely exploratory nature of work in this field with little conceptual framing of results*'. (p.243)

Instruments developed for systematically analyzing medical consultations are most commonly termed "Interactional Analysis Systems" (IAS) which involve coding, quantifying, and scoring audio-recorded patient physician dialogues. The most widely used IASs measure medical based information as well as associated psycho-social functioning such as the Roter Interaction Analysis System (RIAS), CN- LOGIT and the Medical Interaction Process System (MIPS). Use of these systems is limited by their complexity and training requirements (for full review see Ong 2000).

A comprehensive review of all instruments developed for communication analysis is beyond the scope of the current paper. Therefore, summaries of the most commonly used evaluation frameworks within the cancer care setting are presented in tabular form in Appendix 2.1.

The importance of qualitative methods to explore communication

Many of the IASs have shown satisfactory reliability and validity, investigating the quality of the doctor-patient interaction and providing knowledge on patient related outcomes. Typically these have included shared decision making, satisfaction with information, consultation length, eye contact, speech clarity and use of the vernacular (Dunn, 2005).

Qualitative research has shown that use of such methods in studying communication may be based on assumptions that are not congruent with the needs and lived experiences of the patients themselves (Thorne et al. 2005). Another disadvantage of using such methods is that the context seems to be lost because of the separation of information

into coding units, often consisting of one sentence or less (Fagerlind et al. 2008). Increasingly, it has been acknowledged that qualitative methods can be more informative in assessing the communication between the patient and doctor, if tailored to the individual type of cancer consultation (Rodriguez et al. 2010; Fagerlind et al. 2012).

Previously qualitative methods have typically been applied to the process component of the communication framework (Feldman-Stewart et al. 2005) These are: studying the relational aspects of the cancer consultation such as delivering 'bad news', conveying hope, prognosis and shared decision making. As identified by Fagerlind et al. (2012) qualitative approaches allow the results to emerge without being filtered through an existing structured analysis system. Rather than components of a consultation being placed into preexisting categories, the categories are established based on the data whilst coding. This avoids imposing a predefined coding framework upon patient experience, instead allowing the foundations for measuring communication to emerge in this specific group of patients'.

Qualitative content analysis, specifically, has been used to identify patient centered and psychosocial categories to communication analysis systems to supplement their existing validity (Fagerlind et al. 2008). Similarly, by using qualitative content analysis it is possible to identify what topics are being discussed during HSCT consultations and to develop a valid and reliable method of evaluating the HSCT consultation while postulating factors that may influence interpretation of this communication.

Rationale for the qualitative evaluation of communication exchange in HSCT consultations

Until very recently e.g. Fagerlind et al. (2012) there has been a lack of qualitative studies focusing on the communication content in oncology. Fewer still have investigated the communication processes that occur specifically within Haematopoietic Stem Cell Transplant (HSCT) consultations (Merckaert et al. 2009; Grulke and Bailer, 2010; Alexander et al. 2012). Unlike other medical treatments, HSCT is often started early to prevent progression of the illness. However, the procedure also involves a high risk of death and numerous life-threatening side effects such as fatal infections and major organ complications. If individuals' choose to undergo HSCT then they face a short-term risk of fatality in the hope of the possibility of potential cure. Consequently, consultations regarding HSCT tend to be longer and highly emotional due to their complexity and the amount of information which needs to be given to potential transplant recipients regarding treatment options, processes and long- term side-effects. Given

the level of detail, length and focused discussion of treatment options, it is likely in the HSCT consultation there is a higher exchange of information than in many other medical consultations (Alexander et al. 2012).

A review of the literature reflects a divide in terms of meeting patients' informational needs, with some researchers arguing that in-depth and detailed information is necessary for the patient who attends for HSCT consultation. Other researchers argue that basic information about HSCT and its effects is all that is required to meet individuals' informational needs. The need for detailed information is varied and haematological cancer patients express preference for basic information on treatment where HSCT is an option. There is consensus that doctors can tailor the amount and content of information if they are aware of the content that patients most likely remember and understand.

This thesis aims to create a tool capable of identifying and comparing patient recall and understanding with the information they receive from their doctor during consultation for HSCT. The tool will be developed using qualitative content analysis and a coding system grounded in the theoretical framework by Feldman-Stewart et al. (2005) and methodology of relevant research on the topic (e.g. Alexander et al. 2012). In doing so, the complexities involved in assessing patient-doctor communication will also be elucidated. It is important that different assessment frameworks for different types of cancer consultations exist so that their distinctive characteristics can be taken into account. Currently there are no measures for assessing the area of HSCT consultations within the National Health Service (NHS) in Scotland. It is for this reason that it is the central focus of this thesis.

The development of an instrument to capture the experience and nature of doctor-patient communication is essential in gaining knowledge and understanding regarding the content of cancer consultations. Such an instrument would facilitate the delivery of patient centred communication in response to health service standards, particularly for medical procedures involving a high risk of death and a multitude of side effects such as HSCT (Merkaert et al. 2009). No previous studies have set out to understand, describe and measure patient recall and understanding in the context of HSCT consultations in Scotland.

Research aim (s)

The aim of this study is to develop a tool capable of measuring recall and understanding of information given to a patient during consultation for HSCT, thereby contributing to the evidence base of communication measures used in oncology, and facilitating doctor-patient communication resulting in improved care for patients about to undergo HSCT.

Research tasks

The objectives of this research were to:

1) Develop a coding framework capable of evaluating the interaction between the patient and doctor in the HSCT consultation within the haemato-oncology setting, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action;

2) Determine the reliability, internal consistency and content validity of the of the coding framework, hereafter referred to as the Recall and Understanding Interview Template (RUIT), as it is at its current stage of development.

Research design

In addressing the reliability and validity of the RUIT, the researcher went through the processes depicted in Figure 4. Face, content and construct validity were addressed through; a literature review, an existing "work up sheet" currently in use by consultants and expert opinions from Consultants at the Beatson Oncology Centre. Inter-rater agreement was obtained regarding the categories defined and codes applied.

Methods

This qualitative study employed directed content analysis to code and analyse the recall and understanding of communication from the patient-doctor consultation about HSCT (Carlson et al. 2005), and uses pre-determined categories from the recall and understanding interview template (RUIT) (Appendix 2.2).

A challenge to content analysis is the fact that it is very flexible as a result of which there are differences in agreement among researchers over what definitively constitutes content analysis and in particular the difference between qualitative and quantitative content analysis (Schreier, 2012). Therefore, it is the researcher who must judge which research

methods are most appropriate for their particular problem (Carlson et al. 2005) which makes the analysis process more challenging and interesting. While the importance of establishing the methodological rigour of research cannot be overstated, this takes on particular importance when the aim is to improve our understanding of a complex topic, using qualitative methods, which has received little prior attention in the literature such as the evaluation of patient's recall and understanding from a HSCT consultation.

There is a challenge, therefore, to identify ways that are appropriate to the research methods used to ensure transparency. The study used content analysis and it was decided therefore, to use the criteria identified by Guba and Lincoln (1994), to guide approaches to maintaining rigour. In an attempt to address the lack of appropriate criteria on which to judge qualitative research, Guba and Lincoln (1994) devised a set of four assessment criteria that could be used in qualitative and quantitative research studies: truth-value, applicability, consistency and neutrality. These can be defined and operationalised both in qualitative and quantitative research:

Figure 2. Qualitative criteria for rigour and quantitative equivalent terms

Concept	Qualitative	Quantitative	How this is operationalized	Techniques
Truth-value	Credibility	Internal validity	Purposeful sampling, constant comparison, member checking, triangulation, audit trail	Field/personal notes, tape recorder, thematic log, auditing transcript
Applicability	Applicability	External validity	Purposeful sampling, 'thick description'	Data display, simultaneous literature review
Consistency	Auditability	Reliability	Atypical case, triangulation, peer review, audit trail	Field notes, tape recorder. Thematic log, auditing transcript
Neutrality	Confirmability	Objectivity	Audit trail	Field journal

Source: redrawn from Guba and Lincoln (1994)

In addressing the reliability, validity and objectivity of the RUIT, the researcher adhered to the guidelines proposed by Guba and Lincoln (1994) as far as possible. This process is shown in Figure 2. reliability and validity were addressed through literature review, expert opinions and inter-rater agreement on the coding scheme and topics contained within the RUIT. The methods of the study involved 3 distinct phases; each phase of the methods represents aspects of the study. This cumulative process facilitated careful construction and refinement of the RUIT. An outline of this 3-phase process is presented;

1. development and validation of the RUIT

2. pilot study, preliminary findings and RUIT refinement

3. further development and validation of RUIT

Phase 1: Development and validation of RUIT

Item generation for RUIT

Topics for the interview and RUIT coding schedule (Appendix 2.2) were developed based on the following;

a) a review of the literature about measuring communication between health professionals and their patients in health care, more specifically the cancer setting,

b) liaisons with the consultant psychologist and oncologists from the Beatson. The consultant clinical psychologist based at the Beatson Oncology Centre has experience of working with patients who are eligible for or have undergone HSCT. Therefore, the RUIT was refined in discussion with him.

c) prior observation of HSCT consultations.

Sorting the data

The researcher began to sift through the data, identifying tentative hunches and themes. This involved scrutinising the data line by line. Clusters of coded data that fitted together began to emerge and the information collected was read through again. Headings were written down in the margins to describe all aspects of the content (Hsieh and Shannon 2005). Similar topics were grouped under the same over arching heading as shown in Appendix 2.1 and 2.2. The aim of grouping data was to reduce the number of categories

by collapsing those that are similar or dissimilar into broader higher order categories. Examining the information in this way, the researcher was able to come to a decision, through her own interpretation, as to which segments of text/data to put into the same category.

Overall nine main recurrent topics or variables were identified as being of relevance, including: clarification of information pertaining to patient's current/past health and well- being, explanation of the treatment process, aims of treatment, side effects, Graft vs. Host Disease (GvHD), prognostic discussion, impact of treatment on quality of life, practical issues and next steps. These variables each have a number of sub-topics pertaining to the main variable (Appendix 2.2).

Preliminary topics, developed through the literature review and observation of HSCT consultations, were formatted into a draft which was then presented to three Consultant Oncologists and the ethics committee from the Beatson as well as the academic and expert field supervisors who were from diverse professional backgrounds. They explored each topic and corresponding sub topics, content of questions, wording and organisation, noting individual merits and flaws of the target population. Their suggestions were incorporated into the RUIT and a revised draft was submitted for additional feedback.

The recall and understanding interview template (RUIT) was finalised for recording and scoring the agreement between information that was conveyed by the consultant, and then recalled and understood by the patient. This was subsequently used as a coding framework.

Phase 2: pilot study and RUIT refinement

The pilot was conducted at the Beatson West of Scotland Oncology Centre (BWoSOC) NHS Greater Glasgow and Clyde in Scotland. This cancer centre was chosen because it is where the majority of patients requiring HSCT, are referred for consultation.

Recruitment

Participants were considered eligible to participate in this study if it was their first consultation and they were eligible for HSCT, and were referred consecutively to the

Beatson

West of Scotland Cancer Centre (BWoSOC). Haemato-oncology medical staff working with patients undergoing HSCT at the BWoSOC reviewed their database, which indicated that approximately 12 HSCT patients would be available for recruitment within a six-month period. Participants were eligible for inclusion if they met the following criteria:

Inclusion criteria:

- were candidates for HSCT

- were at least 18 years old

- were aware of their diagnosis (e.g. acute or chronic leukaemia)

- if English was their first language

Exclusion criteria. Patients;

- had severe psychiatric morbidity

- had problems with substance misuse

- were unable to provide informed consent

Participants' who were referred for HSCT to the BWoSOC between January 2013 and June 2013, and identified as suitable according to the inclusion criteria (Figure. 3) were sent an invitation letter with an attached 'consent to be contacted by researcher form alongside their hospital letter for initial clinic appointment. Those interested in taking part returned the consent form via a stamped addressed envelope to the researcher. Patients were then contacted individually and the process explained in detail. Interested participants were then given a participant information sheet, a full consent form and relevant pre-consultation questionnaires to complete on the day of their HSCT appointment. This process was outlined in the Participant Information Sheet and in the instruction sheet included in the questionnaire pack. Five participants expressed their interest in participating.

The participants included four males and one female. The mean age at the time of their HSCT consultations was 52 years old (range: 34-62 years). Participants were about to undergo HSCT for a variety of haematological cancers and were all eligible for HSCT.

Two participants were also diagnosed with Myelofibrosis. These participants were included in the study as it was decided that this would not affect the homogeneity of the sample, given that these individuals were both deemed eligible for HSCT in the future. The research aims of this study were therefore still significant for these participants and it was decided that their inclusion in the study would add depth to the findings.

Figure 3. Characteristics of participants

Participant	Age	Gender	Disease type	Diagnosed
1	34	Male	Hodgkin's lymphoma	2010
2	53	Male	Myelofibrosis	2008
3	56	Male	Chronic myeloid leukaemia	2012
4	52	Female	Myelodysplastic syndrome	2011
5	62	Male	Acute myeloid leukaemia	2012

Participants and recruitment method

Within qualitative research, sample size is not predetermined so power calculations are not appropriate. Quantitative research provides the best opportunity to generalise results to the population but the purpose of qualitative research is to gain an in-depth, thorough understanding of the meanings that patients attribute to their experience and to gain an understanding of their perspective) (Barker et al. 2002). In the context of this research, it provides an insight into the individuals' who are required to make decisions about HSCT. Instead of placing the elements of a consultation in predefined categories, using this qualitative approach, themes were established and based on data while coding. Therefore purposive, convenience sampling was used with those who met the selection criteria. A sample size of five participants was deemed feasible and appropriate, taking into account the referral rate, the time available to recruit participants and the range of this research.

Ethics

This study was carried out in accordance with the British Psychological Society's (BPS) Code of Ethics and Conduct (2009). Prior to the commencement of the study, a

standard two-step process was undertaken to receive organisational approval from the BWoSOC (see Appendix 2.3). Full ethical approval was also obtained from the West of Scotland Research Ethics Committee (Appendix 2.4) while management approval was also received from the Greater Glasgow and Clyde Research Development (see Appendix 2.5). Participants were fully informed about the research aims and procedure prior to the collection of their data (see Appendix 2.6). Subsequent ethical approval was also obtained to include patients'with chronic leukaemia (Appendix 2.3). Written consent for the participation, recording and transcribing of interviews as well as the publishing of anonymised quotations, was sought from consultants and all of the participants (Appendix 2.7). Each participant was given a number and all personal information was removed from the study to ensure anonymity and protect confidentiality.

Procedure

The medical consultation (approximately 1 hour) was digitally recorded using a digital voice recorder (DVR). This was located in the clinic room by the researcher prior to the participant and consultant entering the room. Following the consultation, and once the participant left the clinic room, the researcher collected the DVR. The researcher then interviewed the participant using the RUIT in a separate clinic room. This interview was also recorded. Every effort was made to work around patient's schedules. Consent to record the consultation was also sought from the individual Consultant Haemato-Oncologist. Whilst it can be argued that observing in this way may influence participants responses, audio or video recording are considered non-intrusive by nature (Dunn et al. 2005). The present study used a combination of direct (audio recording) and retrospective (semi-structured interviews) observation. Figure 4 shows a preliminary outline of the participant's recruitment and participation in the study.

Data collection

Semi-structured interviews were used to collect data. These were recorded for later transcription. Participants' were firstly invited to freely recall information from their consultation and talk as broadly as possible about their memory of the information they received from their HSCT consultation. It was made clear to the participants that there were no right or wrong answers and there was no expectation that they would be able to recall all

of the information. Clinical skills of active listening, simple reflection and empathy were given priority in order to ensure the interview was as patient-centred as possible. The transcripts were then transcribed ready for anlaysis by the researcher.

Figure 4. Process to address RUIT reliability and validity

Phase 1 (Steps 1-5): Development and validation of RUIT

Phase 2 (Steps 6-10): Pilot study and RUIT refinement

Step 1: Consent sought from patient and doctor to observe clinical consultation and take notes throughout.

Pilot of RUIT with patients attending for HSCT

Step 6: invitation to take part

Mail 30 (n=5)

Step 2: Each observed consultation transcribed, coded and themed using content analysis to create draft template

Step 7: Consultation

Step 8: Post-consultation

Patient Interview Schedule (using RUIT) completed during face-to-face meeting.

Step 3: content analysis of literature for themes added to content of RUIT

Step 9: Interviews audited

Research & Field supervisors explored each transcript & provided feedback

Step 4: RUIT circulated to Consultant Oncologists at Beatson

Step 5: Pilot instrument

Phase 3 (Steps 10-15): Further development and validation of RUIT

Step 11: Problem solving/Developed codes for recall and understanding

Branching sub codes within 3 level structure to capture both recall and understanding

Step 10: RUIT circulated to Consultant Oncologists at Beatson, Research & Field Supervisors for additional feedback

Step 13 Application of coding to transcribed data
Transcripts independently coded blindly in pairs by field supervisor and academic supervisor & compared with RUIT coding framework & agreement reached on analysis process

Step 12: Revised RUIT applied to code interview transcripts

Step 15: Final template

Step 14 Inter-rater agreements

Inter rater agreement obtained (Kappa = 0.83 p<0.01)

Interview schedule

The same interview schedule, based on the RUIT, was used for each patient because individual consultations were very similar. The interview schedule was structured into two main sections, to elicit both spontaneous and free recall. The questions from the first section were open-ended to allow for participants individual interpretations and explorations of the key topics of information that they received during consultations (e.g. "can you talk me through everything you remember the doctor saying to you during your consultation (date)?" and "can you remember anything else?"). These were followed up by focused questions to obtain further information about key topics (e.g. did the consultant talk with you about your health condition/illness? What do you remember the doctor telling you about your health condition/illness?).

All participants were asked the same questions. It was then possible to elicit information from participants regarding different topics of information that were typically discussed during consultations. Examples are; the status of the disease, treatment options, and aims of treatment, donor match, practical issues, side effects, graft vs. host disease (GvHD), and prognosis and course of recovery. The researcher continued to ask questions until satisfied that the patient was unable to recall any more information. This allowed participants to recall as much as they could from the consultation. The semi-structured format is considered appropriate to explore individuals' perceptions of doctor-patient communication and the factors which influence this (Carlson et al. 2005). The researcher was sensitive to the patients' use of language and efforts were made to use their own words to prevent the researcher's own interpretations from influencing participants' responses. Patient interviews took between 20-30 minutes, on average, and were digitally recorded, uploaded onto the laptop and transcribed verbatim, without making any references to people or places.

Research recommends that patients are interviewed immediately after consultations for optimal performance on tests of recall (Carlson et al. 2005). However, to reduce the risk of overwhelming patients, assessment of patient recall and understanding occurred individually with the researcher at a convenient time point between the first and second consultation.

Analysis

Directed Content analysis was used to code and analyse recall and understanding of the communication from the consultation (Carlson et al. 2005) using pre-determined categories from the RUIT. This process involved two main preparation steps: data scrutiny and data comparison. Data scrutiny consisted of separately evaluating each data set; consultation data and interview data to determine key findings in each phase and to structure data in a way that would enable comparison. For further information about the methods of analysis used in this study, refer to Miles and Huberman (1994).

Transcript auditing

The field and research supervisors audited each consultation and interview transcript to ensure accuracy. Whilst this was lengthy process, it was extremely important in allowing the researcher and supervisors to gain familiarity with the data and gain confidence in its overall trustworthiness. The supervisors subsequently disseminated feedback to the researcher and changes to the transcripts format and content were noted and amendments made.

Phase 3: further development and validation of RUIT

Similarly, congruence among supervisors and the researcher as well as consultants at the Beatson Cancer Centre, regarding identification of further RUIT topics and content was also reached and recorded in the researchers field notes (Appendix 3). Following discussion, a major change was identified. The first section, 'information pertaining to patients' current/past health and well-being' was removed as consultants often elicit this information as a means of obtaining a patient's background. Appendix 3 details a full summary of how adjustments were made to the RUIT.

Data scrutiny

A coding sheet was devised for each participant, which contained interview and consultation data. The coding sheet comprised of a table, which consisted of each topic of the RUIT. Two separate columns were generated into which participant and consultation information could be placed after thorough reading of both sets of transcripts. Previous examination of the data had resulted in the identification of eight RUIT topics and 50 sub-topics (Appendix 2.2). Reading the transcribed material through several times, the researcher became immersed in the data. Firstly, RUIT topic categories were identified on the consultation transcripts on a line-by-line basis while indicating RUIT topic code in the margins of the transcripts.

Similarly, RUIT topic codes were applied to the interview transcripts. This was to capture all the possible occurrences of the phenomenon and thereby increase the trustworthiness of the coding framework (Hsieh and Shannon, 2005). As the aim of the research was to develop a tool worthy of assessing the level of recall and understanding of medical/factual information given to patients who attend HSCT consultation, it was decided to analyse only the manifest content, that is the factual information given to patients during their consultation.

Applying RUIT codes to the data

Figure 6. Example of sentence-by-sentence coding from consultation

Consultation transcript text

Consultant: From then on it's a case of dealing with effects of treatment and dealing with effects of the transplant. **1g** *Idea of the chemo is to suppress your Immune System and Bone Marrow it will stop your Bone Marrow (BM) working and will* **3c** *take 2/3 weeks for the new BM to be working during that time your blood counts going to drop down to very low levels so your not going to have white cells in your blood and those are important for protecting you from infection. Platelets help your blood to clot. So you won't have any platelets so* **3c** *you will be at increased risk of infection and you're going to be at increased risk of bleeding. You might need blood transfusions and so you're very vulnerable and so you're looked after in a room in the transplant unit specially designed to protect you from infection. During the time from transplant – no problem wondering around ward but wouldn't want you leaving the ward cause you're in an* **8b** *environment that's designed to protect you and keep you safe no problem getting visitors as long as they don't have coughs and colds or upset tummies.*

Interview transcript text

4P: He said there would be risk of infection more so in first 3 months. But longer you go on less chance of infection. You could feel dizzy; vomiting catch coughs colds and all these kinds of things. You're going to feel ill more immediately after. **Score=1b**

1b = distorted recall

1g = purpose of conditioning treatment

3c = side effects and risks of HSCT

8b = practical implications

The headings and relevant content were then collected from individual transcripts and added to the relevant columns on the coding sheet (Appendix 3.1). Participant recall was subsequently compared to the actual communication in the transcribed audio recordings of the consultation based on the RUIT (Appendix 3.2) categories and level of recall and understanding.

Figure 7. Example coding excerpt from coding sheet

2. Explanation of treatment	Category	Patient transcript	Consultant transcript	Code assigned
Patient able to discriminate how HSCT is different from previous treatments they have had	*B*	*Can have a transplant but that would only be on condition of the...as he said before a suitable donor, remission, and fitness to take the treatment. The other option is more chemo that would put it into remission for about a year or more but it wouldn't offer a cure long term.*	*not as straightforward as recovering from chemo there is the potential for a lot of hiccups along the way. A transplant can cure the leukaemia where the chemo couldn't. Issue with transplant is that it is a demanding process to go through in some ways more demanding than chemo you had already.*	*2 – recoded & agreement reached on complete recall thereon, as participant able to distinguish that transplant has the potential to cure the Leukaemia, whereas chemotherapy wouldn't in the long term.*

Source: redrawn from Appendix 3.2

Data comparison

The second step was data comparison. The researcher used the "contrasting" strategy because this is especially suited for comparing two types of material (Boyatzis, 1998) and because she already had an idea of the information that should be looked for as a result of the RUIT. This involved coding and analysing the level of concordance between information given by a Consultant during consultation and an individual patient's recall and understanding, using the RUIT (Appendix 3.2). Coding was developed through discussions with the field and academic supervisors as well as with an external supervisor.

Coding recall and understanding

A number of difficulties were apparent whilst coding the data, highlighting the complexity of this process. Firstly, it was difficult to differentiate recall from understanding. Recall can be considered simply as repetition of information given in the medical consultation and does not necessarily imply that the patient has understood the information. For example, it is possible to memorise a number or medical term without understanding their meaning. Patients generally find it difficult to understand and recall much of what is said in consultations, and as such the two are likely to be closely linked (Hacking et al. 2013). A rating format similar to that employed in the Rivermead Behavioural Memory Test (Wilson et al. 2008) was applied to code both recall and understanding allowing the coders to differentiate between errors of commission (e.g. misunderstandings) and errors of omission. Sub-codes were devised from the following 3 level structures:

2 = complete; 1a = partial recall, 1b distorted recall; 0a = omission, 0b = fabrication/intrusion

Subsequent to data preparation and organisation onto the coding sheet, an additional column was added (Figure 3) entitled "code assigned". Investigator triangulation, utilising a second investigator to analyse some of the data and compare findings, facilitated the coding process. The above ratings were applied to consultation transcripts for participants one, three and five by the field supervisor and the academic supervisor coded the transcripts for participants two and four. The researcher coded transcripts for all participant interviews and consultations. Initially, similarities and differences in rating application were discussed whilst reading transcripts and team coding in real time.

During team coding, the researcher read through transcripts together with the research and field supervisor and recorded in the margins of the transcript the presence of topics, associated items and the level of recall and understanding. Once each coder was able to create their own example of coding each topic, this was then shared with other coders until consensus was reached regarding each code and sub code. Finally, the researcher coded all transcripts and the field and research supervisors coded a proportion of transcripts. This allowed the calculation of inter-rater agreement regarding codes applied. In total, the process of triangulating coders between the researcher and the field and academic supervisors occurred on 3 occasions. During each meeting the academic supervisor and the researcher independently coded an audited transcript and notes were made and discussion about the application of codes occurred. The congruence or differences of the process were recorded by the researcher in field journal.

Challenges of coding

Mapping participant interview information onto consultation data was a complex process that required moving back and forth between the two data sets. There were a number of difficulties encountered during this process. For example, some participants used colloquial terms rather than the medical terminology used by consultants or the researcher. In addition they did not necessarily recall information verbatim from their interview in the order it was prompted and in the way used by their consultants or the RUIT interview schedule and by the researcher. Therefore, application of the codes to determine the accuracy of recall and understanding required the raters to make interpretations, which may have been confounded by their subjectivity. Although this resulted in disparity of how codes were applied, the raters discussed each instance of coding for elucidation and/or clarification until saturated. At this point agreement was reached and/or disagreements were recorded in field notes. Agreement was facilitated because of the researchers close relationship with the data, through constant comparison

of the information and knowledge of the participant's emotions and body language as recorded in field notes. It could be argued therefore that through this process, consistency of applying the ratings emerged and this enhanced the validity of the RUIT. For the purposes of transparency, comments to the coding column, as depicted in Appendix 3.2, have been added describing the process of agreement among coders. To enhance the transparency of the coding process, detailed instructions describing the application of the coding system and categories can be found in Appendix 3.3.

Results

Inter-rater agreement

In the final, RUIT eight categories, with 50 sub-categories of information, were included. The researcher scored the transcripts according to the coding system and the field and academic supervisors also scored a proportion of the transcripts. An inter-rater reliability analysis was subsequently performed using Cohen's Kappa for each code using Landis and Koch's (1977) classification 0.21–0.40, fair agreement; 0.41– 0.60, moderate agreement; 0.61–0.80, substantial agreement; 0.81–1.0, near-perfect agreement. Kappa statistics demonstrate the degree to which two or more raters agree that the coding system measures target variables (8 topics contained in RUIT), in this instance the patient's level of recall and understanding of the RUIT topics. The resulting index compares the recorded agreement with that expected by chance.

The following formula was used: $\kappa = \dfrac{n_a - n_\varepsilon}{n - n_\varepsilon}$ where n = number of subjects, na = number of agreements and $n\varepsilon$ = number of agreements due to chance.

Figure 8. Inter-rater agreement for coding system for RUIT framework

RUIT topic	Inter-rater agreement
Explanation of treatment process	0.67
Aims of treatment	0.55
Side effects of treatment	0.95
Graft vs. Host Disease	0.88
Prognostic discussion	0.83
Impact of treatment on QoL	0.82
Practical issues	0.95
Next steps	1.0
Overall inter-rater agreement	0.83

There was moderate agreement, among raters for the aims (Kappa=0.48, $p<0.01$) and explanation of treatment (Kappa=0.67, $p>0.01$) topics of the RUIT. There was substantial agreement subsequently for the remaining topics indicating that the RUIT coding sytem was consistent in its application across topics: side effects of treatment (Kappa = 0.95, $p<0.01$) graft vs. host disease (Kappa=0.876, $p<0.001$), prognostic discussion (Kappa=0.829, $p<0.001$) impact of treatment on quality of life (QoL) (Kappa=0.815, $p<0.001$), practical issues (Kappa=0.95, $p<0.01$) and next steps (Kappa=1.0, $p<0.01$).

Overall inter rater agreement was calculated as the mean of the inter-rater agreement scores for all categories on the RUIT and served as an index of content validity (Kappa=0.83, $p<0.01$). A more substantial breakdown of inter-rater agreement of topics and subtopics of the RUIT can be found in the appendix (appendix 3.4).

Results part two: participant reflections of the consultation

Some participants openly reflected about the consultation. Their reflections included; comments about the consultation length, consultant's communication style and emotional reactions associated with the content.

"I think he was pretty comprehensive in what he had to say but taking it all in for the last

10 minutes or so I turned off deliberately. So thought had enough of this because to large extent it's doom and gloom. It's not that I don't want to be knowledgeable but at the end of the day it's just that's what I found" (Participant 5a)

This participant admitted consciously filtering out negative information (e.g. risk of mortality) relating to the prognostic information. The quotation not only emphasises the apprehension associated with hearing life-altering information, but also this participant's need to protect himself from the potential negative impact on his mood.

"The only thing I would say is that it was an hour, which I was expecting, but an hour of full- on information really, without time to stop and think, and think whether there's anything you want to ask relating to that. Although, with respect, at the end when I looked at my list of questions everything had been covered, but it's just that it's all very much funnelled into one hour and it's a whole load of information to take on board without time to think about it, maybe in stages." (Participant 4a)

Another participant commented on the length and structure of the consultation. This quotation suggests that the participant struggled to retain the information given to them, and sought a more interactive style of communication from the consultation. Similarly, another participant also expressed that the information was *"quite hard to take in"* (Participant 3a).

"The words 'death' and 'life threatening', obviously, you're going to feel, I could feel my stomach churning a little bit." (Participant 3b)

Similarly, another participant described the life threatening information given during the consultation left him feeling anxious. It is evident from this quotation that the participant's initial expectations were not met and therefore, added to his apprehension, was a sense of disappointment.

"And I do think you need someone writing it down, which he did (participant's husband) cause I think if you were in on your own and trying to assimilate all that information and remember it all it would be difficult, whereas you can go back and look at some of it...You should give us a copy of this was what she actually said so that you can listen to it again afterwards." (Participant 5b)

Finally, one participant also reflected on their information requirements, stating that the

use of information aids would aid their recollection of information from the HSCT consultation. This participant further recommended the use of an audio CD, which she could then listen to at her own leisure, to facilitate her recollection of the information given.

Summary

Application of the recall and understanding coding system to RUIT topics among coders revealed discrepancies in the classification of information. Results show two categories; explanation of treatment process and aims of treatment, which did not meet substantial agreement. It is not known whether discrepancies within categories that did not meet these criteria were either lacking clarity in their description or other factors related to the patient or doctor may have influenced the communication and interpretation of information given to the participant during HSCT consultation.

Discussion

The purpose of this research was to develop a coding framework for measuring the interaction between doctors and their patients who are about to undergo HSCT transplant for leukaemia or other blood disorders. This study has reported the development and testing of a coding framework, the RUIT template and coding system, and in doing so, elucidated the methodological issues and some of the challenges of conducting research in the haemato- oncology setting. The procedures undertaken in developing the RUIT demonstrate reliability and content validity. Further testing through piloting the instrument, indicated that the RUIT coding system has strong inter rater agreement.

Factors influencing the interpretation of the communication

Kessels (2003) reported that 40-80% of medical information presented to patients by health care professionals was immediately forgotten by patients. These figures were influenced by a combination of consultant and patient factors, including the use of medical terminology and patient's emotional state, older age or cognitive difficulties. In addition, if they had previously received treatment for cancer, this may have resulted in cognitive impairment (Friedman et al. 2009). Thus, many variables, including both consultant and patient iatrogenic

factors, can influence doctor-patient interactions. Within the field, however, research has predominantly focussed on consultant communication skills and their impact on patient satisfaction more generally. Multiple studies have shown that patient characteristics as

well as a doctor's style of communication influence the communication and interpretation of information given to patients during cancer consultations (Thorne et al. 2005; Hack et al. 2005; Hagerty et al. 2005; Butow 2000; Fagerlind et al. 2012).

Clinician characteristics

Whilst communication skills training has broadened to incorporate shared decision making, information exchange, enhancing the doctor patient relationship and responding to the emotional tone of the consultation, there remains a need for health care professionals to tailor information giving to meet individual patient's needs (Jenkins et al. 2011). However, difficulties in communication can arise as a result of differences in goals among health professionals and patients.

Compassion fatigue, and diminished empathy may result in clinicians 'burning out', with a negative impact on their ability to deliver information in a patient- centered way (McLean et al. 2011). The authors concluded that the psychological state and predisposition towards optimism of both doctors and patients might influence the communication and its interpretation. The findings of this study are consistent with previous research suggesting that both healthcare professionals and the patients are influenced by pre-existing attitudes, systemic and cultural beliefs and values as well as by their friends and family members (Carlson et al. 2005). For the population under investigation, a family member accompanied almost all participants to their consultation for HSCT. The needs of family members and carers interact with the needs of patients. Although not considered in Feldman-Stewart et al.'s (2005) framework, they were apparent in the narratives of the population under investigation.

Patient characteristics

It was clear that participants experienced anxiety during their consultation and reported actively "switching off" at points to avoid experiencing the associated "doom and gloom". Patients with advanced cancer often experience strong emotions such as sadness, anxiety and fear throughout the course of their illness (Derogatis et al. 1983), which can cause a loss in memory function (Blaney, 1986) and impact adversely upon the patient's ability to recall information given during cancer consultations (Carlson et al. 2005). Specifically, Kizilbash et al. (2002) reported that depressive symptoms (with or without anxiety) have a negative impact on the ability to immediately recall new

information but not on the retrieval or retention of information.

Anxiety can both inhibit or facilitate recall and understanding of information given during medical consultations. Kessels (2003) explains this phenomenon in terms of "attentional narrowing". This occurs when information or events perceived as aversive (e.g. side effects of treatment), become the primary focus of attention. This may cause anxiety and limit the patient's attention towards information they perceive as being less important, allowing them to "focus on" salient pieces of information and thereby experience an enhanced memory of it. Information perceived as upsetting may cause patients to become overwhelmed, and this may impact adversely on their ability to cognitively process information that they receive during consultations. Patients may believe that they lack information, consequently causing feelings of uncertainty, anxiety and depression (Ong et al. 2000). Both very high and low levels of anxiety can lead to lower recall of information, with moderate levels resulting in optimal performance in tests of recollection (Ley, 1988).

Two participants also commented on the length, content and structure of the consultation, stating that the volume of information given was difficult to process. A comprehensive review of the literature (Fallowfield and Jenkins, 1999) revealed, in several ways, good evidence that the structure and content of the consultation influences the patient's ability to remember what has been said, in the following ways:

1) Patients usually recall facts provided at the start of a consultation more readily than those given later;

2) Topics deemed most relevant and important to the patient (which might not be those considered most pertinent to the doctor) are recalled most accurately;

3) The higher the number of statements made by a doctor, the smaller the mean percentage recalled by the patient;

4) Items that patients do manage to recall do not decay over time, as do other memories. In fact, many patients have verbatim recall of what they believe the doctor to have said.

On the other hand, research demonstrates that cancer survivors who have received

radiotherapy and chemotherapy can experience impaired memory as a consequence of these treatments (Joly et al. 2011). Asher's (2011) review of cognitive dysfunction among cancer survivors reported that individuals' with acute leukaemia and myleodysplastic syndrome can experience impairments before treatment, including deficits in memory and learning, processing speed, aspects of executive functioning and upper limb dexterity. This review also suggests that cognitive impairment may also be explained by anxiety, depression and fatigue which are common symptoms experienced by the cancer population.

Clinical implications

The results of this research have implications for clinical practice, especially in relation to the involvement of patients in their preference for information about HSCT. Through developing and piloting the RUIT and coding system, it was apparent that clinicians did not consistently convey the psychological impact of HSCT. This finding was disappointing given that the literature pertaining to communication goals and the needs of cancer patients suggests that cancer treatment outcomes are enhanced when health professionals attend to the emotional needs of their patients (Fagerlind et al. 2008, Thorne et al. 2005), and are facilitated by the use of empathic and informative language (Butow et al. 2000). This is of particular importance in relation to the population under investigation, given the often intense emotional experience associated with life-threatening conditions and treatment (Rodriguez et al. 2010) and increasingly in the context of the provision of HSCT related information and support becoming the role of clinical nurse specialists (Rood et al. 2014).

In overcoming such barriers, for example, doctors could use the RUIT tool to plan the structure and content of the consultation. This would allow doctors of varying clinical expertise and clinical nurse specialists within NHS Greater Glasgow & Clyde (NHS GG & C) to use the RUIT to provide additional information onspecific topics, as an aide memoire in clinical practice.

During their interviews, participants reflected on the structure and content of sessions in relation to remembering and understanding the information from the consultation, in particular, the large amount of information provided, medical terminology used, length of the session and opportunity to ask questions throughout the consultation. These results support the findings of Rood et al. (2014) who found that patients with haematological malignancies vary in the amount of information they require and that basic information,

tailored specifically to their needs, on diagnosis, treatment, prognosis and other topics may be all that is needed to meet their informational needs.

For example it is possible that the RUIT could be used post consultation by the nurse specialist to check and clarify patient understanding of information about HSCT. This would benefit patients and the service alike giving opportunity to correct any potential misunderstandings. Using the RUIT in this way would create a culture within the Hemato-oncology setting whereby nurse specialists could ensure that the correct information was given to patients but also educate the patient on HSCT. This could be formalised into an intervention implemented by a nurse navigator (Thygesen et al. 2011) and its effectiveness investigated more rigorously through a randomised control trial.

Limitations

To reduce the possibility of biasing the results, as is frequently the challenge in qualitative research, the research design and outcomes were mapped against Guba and Lincoln's (1994) trustworthiness criterion for qualitative research. The research strategies and operational techniques to achieve auditability, transferability, credibility and confirmability have also been detailed.

The researcher acknowledges she undertook multiple roles as part of this research. The researcher fulfilled the role of interviewer, coder and principal investigator, with the potential to bias interpretation of findings. However, systematic bias was countered through auditing transcripts, member checking and triangulation. Validity was maximised through investigator triangulation, whereby the field and research supervisors coded and analysed all transcripts, discussing, and comparing until agreement was reached or disagreements recorded regarding the codes applied, thus enhancing 'trustworthiness' in the findings. In terms of transferability it has been proposed that consideration of the findings can be left with the reader to decide which aspects of the case apply in new contexts; therefore it is the reader not the researcher that makes the generalisation (Lincoln and Guba, 1994).

A consultant clinical psychologist specialising within oncology, who is also an experienced field supervisor oversaw the validity of the RUIT coding framework and process of analysis. Feedback regarding the RUIT framework was also gained from experienced consultants

within the field of HSCT and the content was subsequently revised prior to and after the RUIT was piloted. Experienced research supervisors guided the development of the coding and classification system. Validity could also have been strengthened through data source triangulation, for example by combining participant data with consultants' predictions of participant recall and by understanding or by surveying topics of information imparted to them about HSCT, that are of most significance and by comparing both sets of information (Jenkins et al. 2011). Credibility in the findings could also have been enhanced through actively seeking participant views about their involvement in the study, and participation in the interview itself.

Conclusions

This study demonstrates the complexity of designing, refining and implementing a tool to measure patient recall and understanding of the HSCT consultation, based in an outpatient haemato-oncology clinic at the Beatson Oncology Centre in Glasgow. It is also the first qualitative investigation of patients' recall and understanding of content from a HSCT consultation using the RUIT tool.

The criteria developed by Guba and Lincoln's (1994) describes the procedures undertaken in developing the tool to demonstrate rigour through ensuring inter-rater reliability, and content validity. The pilot study further indicated that the RUIT is highly reliable and has internal consistency. However, upon a closer inspection of the individual RUIT categories 2 topics did not meet substantial inter-rater agreement. The process of generating a tool that demonstrates truthfulness, credibility, auditability and conformability for surveying patient recall and understanding in the context of HSCT consultations, may help to identify the information needs of patients, using a reliable means.

Throughout the pilot of the RUIT participants also told of their experiences of the content, and structure of the HSCT consultation as well as the communication behaviours' of the consultants'. An awareness of patient opinion regarding the consultation may enable services to ally themselves with the patient, providing accurate and relevant information, where possible. This investigation provides an initial summary of the development and validation of a tool to measure doctor patient communication in the haemato-oncology setting which points out the necessity to distinguish aspects of the consultation that are easily misunderstood so that support can be planned that may help

patients' to remember and understand information given to them during consultation. In doing so, services can best attempt to meet the informational needs of haematological patients' in a personalised manner.

Implications for future research

To obtain a better understanding of haematological patients' recall and understanding of HSCT consultations, future studies will require to consider the following:

- Firstly the interview schedule will require some adjustment to match the RUIT categories and be re-piloted to strengthen reliability and validity. For items on the RUIT that did not meet the criterion, they may require elimination or modification to increase clarity for future use in such research;

- Secondly, future research may focus on measuring recall only for the 'important points' of the consultation and asking both patients and doctors what those points are;

- Finally, some researchers have suggested that verbatim recall does not necessary result in understanding and sometimes, and for certain types of information, knowing the 'gist' is good enough or better (Jansen, 2008). Researchers, therefore, might ask oncologists to summarise the most important points that were discussed in each consultation and make a tailored recall questionnaire based on that information (Jenkins et al. 2011). As such, future research may focus on devising a tailored questionnaire based on the items discussed rather than using the same RUIT interview for each consultation.

Future research may also employ a mixed methods correlational study design, with a larger sample that may add to our understanding of the links between psychosocial factors and the level of patient recall and understanding. Comparing the use and experiences of information aids (e.g. audio CD of consultation) with no intervention, with prospective HSCT patients', would also, perhaps, provide a more definitive argument for the effectiveness of information aids with patients about to undergo HSCT. In addition to this, a significant other person accompanied all patients and it may also be useful to include them in such future research.

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CHAPTER THREE

ADVANCED PRACTICE I – REFLECTIVE CRITICAL ACCOUNT

"Connecting the dots" - The development of core therapeutic skills:
A Reflective Account

ABSTRACT

Working as a reflective clinical psychologist is considered a core competency of the profession. Hence the emphasis placed on doctoral training programmes to facilitate this practice both during and post qualification. In line with these requirements the present reflective account is a representation of my learning and development during training. The present account focuses on the development of my communication and clinical skills within differing settings through the use of three consecutive learning experiences. Specifically these experiences emphasise how my skills in applying and communicating evidence based psychological knowledge, theories and skills have evolved throughout training and future intentions in continuing to do so are interspersed throughout the account. In particular this account attends to my reflections of integrating psychological models rooted in systemic and attachment approaches. I have used Rolfe's model (2001) of reflection as well as others that are developmentally (Stoltenberg et al. 1998) and systemically (Hawkin's and Shohet, 2012) based, also taking into consideration wider ethical and policy related factors that have impacted upon my professional understanding and development.

CHAPTER FOUR

ADVANCED PRACTICE II – REFLECTIVE CRITICAL ACCOUNT

The multi-faceted role of the clinical psychologist in the Multi-Disciplinary Team (MDT): A Reflective Account

ABSTRACT

Contrary to my first reflective account, which focused on the application of my clinical skills, this second reflective account provides a description of my experiences on my placement fulfilling training and consultancy roles as well as supporting others in the delivery of psychological interventions as part of the Clinical Psychologist's role whilst working in Psychiatric Rehabilitation in my 3rd year. I also attempt to give a rationale for these roles of the clinical psychologist in the context of increasing access to psychological therapies in Scotland. I have used Rolfe et al.'s (2001) model of reflection embedded within Hawkins and Shohet's 'Seven Eyed' supervision model (2006) to guide my reflections of this experience.

Appendix 1 European Journal of Cancer Care Guide to Authors

For more details access:
http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/homepage/ForAuthors.html

Appendix 1.1: Excluded papers following inclusion/exclusion criteria

Reference	Reason
McJannett, M., Butow, P., Tattersall, M., & Thompson, J. (2003). Asking questions can help: Development of a question prompt list for cancer patients seeing a surgeon. *European Journal of Cancer Prevention, 12*(5), 397-405.	Includes views of health professionals as well as patients
Iredale, R., Rapport, F., Sivell, S., Jones, W., Edwards, A., Gray, J., & Elwyn, G. (2008). Exploring the requirements for a decision aid on familial breast cancer in the UK context: A qualitative study with patients referred to a cancer genetics service. *Journal of Evaluation in Clinical Practice, 14*(1), 110-115.	Patients are at risk of Breast cancer no diagnosis
Korber, S. F., Padula, C., Gray, J., & Powell, M. (2011). A breast navigator program: Barriers, enhancers, and nursing interventions. *Oncology Nursing Forum, 38*(1), 44-50.	English not first language for 1 person in sample
Shepherd, S. C., Cavers, D., Wallace, L. M., Hacking, B., Scott, S. E., & Bowyer, D. J. (2012). 'Navigation' to support decision making for patients with a high grade brain tumour. a qualitative evaluation. *Neuro-Oncology, 14*, 4-4.	Abstract/poster for conference

Appendix 1.2: Quality Rating Form

Stage	Essential criteria	Present	Absent
Scope and purpose	- Clear statement of focus for research - Rationale for research - Questions/aims/purpose - Study thoroughly contextualised by existing literature		
Design	- Method/design apparent - Above consistent with research intent - Rationale given - Data collection strategy apparent - Data collection strategy appropriate		
Sampling strategy	- Sample and sampling method explained - Above justified - Above appropriate		
Analysis	- Analytic approach explained - Above appropriate - More than one researcher involved if appropriate - Participant involvement in analysis - Evidence of data saturation/discussion or rationale if did not		
Interpretation	- Context described - Context taken account of in interpretation - Clear audit trail (sufficient so others can follow decision trail) - Data used to support interpretation		
Reflexivity	- Researcher reflexivity demonstrated		
Ethical dimensions	- Ethical approval granted - Documentation of how consent was managed - Documentation of how confidentiality and anonymity were managed		
Relevance and transferability	- Relevance and transferability evidence - Links to theories and literature - Limitations/weaknesses outlines - Outlines further directions for research		
Notes:			

Quality Rating Criteria (redrawn from Walsh & Downe, 2006)

Appendix 2.0 European Journal of Cancer Care Guide to Authors

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Appendix 2.1 Reliability and validity of Interactional Analysis Systems (IASs)

Tool	Authors	What does it measure?	Methods of evaluation	Inter-rater reliability/validity	What is analysed?	Special notes
Cancer-specific Interaction Analysis System (CN-LOGIT)	Butow et al (1995)	Interaction of cancer patients and oncologists. Coding content & mood of each utterance	Computerized interactional analysis of transcriptions of audio- taped interactions; retains sequence of events	Inter-rater reliability 0.70–1.00 Face validity has been demonstrated; convergent validity measured (no correlation with patient satisfaction found)	Verbal content, mood & non verbal behavior	Required extensive analysis of transcripts; coders must be trained
MIPs Global Scale	Ford et al (2000)	As above	As above	Ranging from 0.88 to 0.94	Verbal content, mood & non verbal behavior	Requires extensive analysis of transcripts: coders must be trained
Roter Interaction Analysis System (RIAS)	Roter & Larson (2002)	As above	Coding directly from audio or video tape	0.85 (mean)	Verbal & non verbal behavour	Coders must be trained Coding is performed in real time

Observer-checklist (OC)	Simonoff et al 1989 & 1991	Treatment related topics initiated by doctor or patient or lack of	Coding directly from audio or video tape	0.88. validity could not be retrieved	Verbal behavior only	Influence of observer Generalizability limited to breast cancer population
Physician behavior checklist (PBCL)	Blanchard et al (1983:1988: 1996)	Oncologist behaviours during brief doctor-patient encounter (rounds)	Coding directly from audio or video tape	Ranging from 0.85 to 1.00. validity could not be retrieved	Verbal and non verbal behavior	Requires observer to code in real time

Appendix 2.2: Recall and understanding information template (RUIT) framework Version 1.1

1. Treatment

Explanation of process:

   a. indications for VUD transplant – suitability of illness type/stage, age, donor availability, disease in remission (BMA), fitness.
   b. How is a VUD transplant different from previous treatments may have received?
   c. Tests required pre-transplant and reasons for these – heart, lung, kidney, liver
   d. Finding a suitable matched donor, VUD or sibling
   e. Notice period for donor. Likely transplant dates
   f. Stem cell harvesting – how this happens, how much is needed
   g. Conditioning treatments – reduced intensity/Myeloblative; what agents are used, over what period of time
   h. What happens – IV transfusion of cells through Hickman line
   i. Anticipated length of hospital admission – indications of when suitable for discharge

2. Aims of treatment
   a. explanation of purpose and intention of transplant

3. Side-effects of treatment

Acute effects

   a. what to expect – week 1, weeks 2-3, week 4-5
including following: high temperature, rash, rigors, mucosistis, stomach/abdominal pain, diarrohea, nausea/vomiting, fatigue, hair loss, reduced concentration/memory, increased infection risk

   b. side-effects of steroids – lose muscle, gain fat, increased BP etc
   c. estimation of length of time takes for immune system to recover
   d. risk of complications diminishing over time

Late effects

   e. endocrine, cardio-vascular, secondary cancers, fertility, loss of libido, cataracts
   f. how these are screened for and managed – i.e. late effects clinic

108

g. preventative behaviours – stop smoking, high factor sun protection, bowel screening

4. Graft vs. Host Disease (GvHD)

Acute GvHD

a. what is it/why does it happen?

b. Grading

c. Symptoms – skin, liver, gut, appetite etc

d. Chances of acquiring acute GvHD – mild, moderate, severe

e. How this is prevented/managed

f. Implications of GvHD

g. Graft vs. Leukaemia Effect – explanation and implications

Chronic GvHD

h. symptoms

i. management

5. Prognostic discussion

establish what information the patient requires

a. treatment related mortality

b. relapse

c. disease free survival

d. estimation of morbidity/mortality without transplant

6. impact of treatment of quality of life
    a. psychological
    b. social
    c. financial/vocational

7. practical issues
    a. named consultant/team approach
    b. clean environment – issues around visitors, young children, single room, infection control – aprons, hand gel
    c. relative overnight accommodation
    d. transport
    e. donor lymphocyte infusion

108

    f. long-term anti-microbial therapy

    g. change of blood group

    h. re-immunisation

    i. sperm banking

    j. possible need for re admission

    k. friends of the Beatson

    l. outpatient follow up arrangements

    m. support needs post discharge

8. Next steps

    a. consent form – read over

    b. have a look around the unit

    c. read over booklet before next appointment

    d. take bloods

Appendix 2.3 West of Scotland Research Ethics Approval

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Dr S.L Wilson	Date	18th January 2013
Senior Lecturer In Health Psychology	Your Ref	
University of Glasgow	Our Ref	
Mental Health and Wellbeing	Direct line	0141 211 2123
1st floor, Administration Building	Fax	0141 211 1847
Gartnavel Royal Hospital	E-mail	Liz.Jamieson@ggc.scot.nhs.uk
1055 Great Western Road		
Glasgow		
G12 0XH		

Dear Dr Wilson

Study title:	**An exploration of the recall and understanding of information given during a consultation with a Haemato-Oncologist, of patients who are due to undergo Voluntary/Unrelated Donor(VUD) transplant for acute leukaemia.**
REC reference:	**12/WS/0310**
Protocol number:	**GN12CP481**
IRAS project ID:	**106712**

Thank you for your recent email. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 19 December 2012

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	2.0	19 December 2012
Participant Information Sheet	2.0	19 December 2012

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		
Interview Schedules/Topic Guides	1	28 November 2012

108

Investigator CV		01 May 2012
Letter of invitation to participant	1	28 November 2012
Other: Initial Letter of Invitation	1	28 November 2012
Other: Codebook Definitions		
Other: CV - Sheznaz Iqhal		28 November 2012
Other: Correspondence from Clinical Governance		
Participant Consent Form: Observations of Consultations - Patient	1	28 November 2012
Participant Consent Form: Observations of Consultations - Consultant	1	28 November 2012
Participant Consent Form	2.0	19 December 2012
Participant Information Sheet	2.0	19 December 2012
Protocol	2.0	09 November 2012
Questionnaire: Validated - HADS		
Questionnaire: Validated - FACT		
REC application		28 November 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/WS/0310	Please quote this number on all correspondence

Yours sincerely
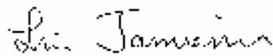
Liz Jamieson

Mrs Liz Jamieson
Committee Co-ordinator

Copy to: Dr Nathaniel Brittain, Research and Development - NHS Greater Glasgow and
             Clyde

Appendix 2.3 West of Scotland Research Ethics Approval   (Amendment)

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Dr S.L Wilson	Date 31st May 2013
Senior Lecturer In Health Psychology	Your Ref
University of Glasgow	Our Ref
Mental Health and Wellbeing	Direct line 0141 211 2123
1st floor, Administration Building	Fax 0141 211 1847
Gartnavel Royal Hospital	E-mail Liz.Jamieson@ggc.scot.nhs.uk
1055 Great Western Road	
Glasgow	
G12 0XH	

Dear Dr Wilson

Study title:	**An exploration of the recall and understanding of information given during a consultation with a Haemato-Oncologist, of patients who are due to undergo Voluntary/Unrelated Donor(VUD) transplant for acute leukaemia.**
REC reference:	**12/WS/0310**
Protocol number:	**GN12CP481**
Amendment number:	**AM01/1**
Amendment date:	**22 May 2013**
IRAS project ID:	**106712**

Thank you for submitting the above amendment, which was received on 23 May 2013. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 17th May 2013 refers).

The modified amendment was reviewed by the Sub-Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

The Sub Committee noted that you no longer wanted to change the recruitment process in line with that detailed in the previous Substantial Amendment. You did however wish to amend the inclusion criteria to cover 'chronic' as well as 'acute' patients.

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Protocol	3.1	22 May 2013
Modified Amendment	AM01/1	22 May 2013

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

12/WS/0310:	Please quote this number on all correspondence

Yours sincerely

Liz Jamieson

Liz Jamieson
Committee Co-ordinator
On behalf of Eoin MacGillivray, Vice Chair

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Nathaniel Brittain, R&D – NHS Greater Glasgow and Clyde

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West of Scotland REC 3

Attendance at Sub-Committee of the REC meeting on 05 June 2013

Name	Profession	Capacity
Ms Susan Fleming	Public Health Researcher	Expert
Mr Eoin MacGillivray	Retired Dentist - Vice Chair	Expert
Mrs Rosie Rutherford	Lay Member	Lay

Also in attendance:

Name	Position (or reason for attending)
Mrs Liz Jamieson	

Appendix 2.4: NHS Greater Glasgow and Clyde Research and Development Management Approval

NHS
Greater Glasgow and Clyde

Coordinator: Dr Nathaniel Brittain
Telephone Number: 0141 211 8544
E-Mail: Nathaniel.Brittain@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

21st January 2013

Dr Sarah Wilson
Mental Health and Wellbeing
1st Floor, Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

NHS GG&C Board Approval

Dear Dr Wilson

Study Title:	An exploration of the recall and understanding of information given during a consultation with Haemato-Oncologist, of patients who are due to undergo Voluntary/Unrelated Donor (VUD) transplant for acute leukaemia.
Principal Investigator:	Dr Sarah Wilson
GG&C HB site	Beatson West of Scotland Cancer Centre
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN12CP481
REC reference:	12/WS/0310
Protocol no: (including version and date)	Version 2.0 – 09/11/2012

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

   a. During the life span of the study GGHB requires the following information relating to this site

      i. Notification of any potential serious breaches.

      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

Delivering better health

www.nhsggc.org.uk

Page 1 of 2   NHS GG&C Board Approval_GN12CP481

Greater Glasgow and Clyde
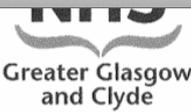
2. **For all studies** the following information is required during their lifespan.
   a. Recruitment Numbers on a quarterly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial
   d. Notification of Trial/study end including final recruitment figures
   e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Dr Nathaniel Brittain
Research Co-ordinator

Cc: Shehnaz Iqbal, Trainee Clinical Psychologist, Gartnavel Royal Hospital

Appendix 2.5   NHS Greater Glasgow and Clyde Research and Development Management Approval

Dear Dr Wilson,

R&D Ref: GN12CP481   **Ethics Ref**: 12/WS/0310
Chief Investigator: Dr Sarah Wilson
Project Title: An exploration of the recall and understanding of information given during

a consultation with Haemato-Oncologist, of patients who are due to undergo

Voluntary/Unrelated Donor (VUD) transplant for acute leukaemia.

Protocol Number: Version 3.1 - 22/05/2013
Amendment: Substantial Amendment 1 (22.05.2013)
Sponsor: NHS Greater Glasgow and Clyde

I am pleased to inform you that R&D have reviewed the above study's Amendment and

can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated	Rec'd
REC Favourable Opinion Letter	No Version	31/05/2013	31/05/2013
Notice of Amendment	IRAS v3.5	22/05/2013	22/05/2013
MRP Proposal	V3.1	22/05/2013	22/05/2013

I wish you every success with this research project.

Yours sincerely,

Dr Nathaniel Brittain
Academic Research Coordinator
NHS Greater Glasgow and Clyde
Research and Development Central Office
Tennent Institute
38 Church Street
Glasgow
G11 6NT

Tel: +44 (0)141 211 8544
nathaniel.brittain@ggc.scot.nhs.u
k www.nhsggc.org.uk/r&d

Please note that I do not work Fridays

Cc: Shehnaz Iqbal, Trainee Clinical Psychologist, Gartnavel Royal Hospital

108

**Factors Influencing Patient Recall and Understanding of Haemato-Oncology
Consultations: An exploratory study.**

Participant Information Sheet

Correspondence to:

Shehnaz Iqbal

Trainee Clinical Psychologist Mental

Health and Wellbeing

1st floor, Administration Building

Gartnavel Royal Hospital

1055 Great Western Road GLASGOW

G12 0XH

FACTORS INFLUENCING PATIENT RECALL AND UNDERSTANDING OF HAEMATO-ONCOLOGY CONSULTATIONS

Participant Information Sheet

Introduction

My name is Shehnaz Iqbal and I am a Trainee Clinical Psychologist studying at the University of Glasgow. I would like to invite you to take part in a research study. This study will be undertaken as part of a doctorate degree. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and feel free to discuss it with others if you wish.

Please ask me any questions you have. You can phone me on the following number (*0141 301 7324*) or you can leave a message and I will get back to you as soon as possible.

What the study is about

This study is an exploration of the factors which influence people's remembering and understanding of the information they receive during medical consultations. I am interested in understanding the factors that might influence how much information you can remember, and the types of information you forget after your hospital consultation about bone marrow transplant (BMT). This type of research might help to identify factors that influence recall and understanding of medical information, and help us to think of ways we could help patients gain as much as possible from their appointments.

Why you are being asked to participate

We are asking adults with acute leukaemia who will be attending the Beatson West of Scotland Cancer Centre for their first bone marrow transplant consultation to take part in this study. You are being invited to participate because you are due to attend the BMT clinic in the near future.

Do I have to take part?

No. You do not have to take part in this study. It is up to you to decide whether or not you wish to participate in the study. If you decide to take part you will be asked to sign a consent form. The consent form is a way of making sure that you know what you have agreed to. If

you decide to take part you are still free to withdraw from the study at any point in time. If you decide to withdraw from the study, this will not affect your on going medical care in any way.

Taking part in the study – what will I have to do?

If you decide to take part, I will arrange to meet with you on two occasions; before and after your medical appointment at the Beatson West of Scotland Cancer Centre. Prior to your medical consultation, I will meet with you to explain what you are consenting to, and if you are happy to proceed, ask you to sign the consent form. You will be providing consent to agree to have your medical consultation and subsequent interview with me recorded (to make sure that I carefully understand your experiences, the conversations you had with your consultant, and help me remember all the things we talked about). The interview after your medical consultation will last for a maximum of 30 minutes. During this meeting I will ask you questions about the information you received about your transplant. There are no right or wrong answers, the research just wants to learn more about your own experience of the types of information you remember and understand from your consultation. If you would prefer to discuss this in the form of a telephone interview, then I will arrange a suitable time to call you. Our conversation will be recorded using a telephone recording device. With your permission, anonymous quotes of what you have said may be used in the report.

Is there a down side to taking part?

It is possible that our meeting may cover topics that are difficult or upsetting to talk about. However, if you do not want to continue, you can end the interview, or have a break, at any time. If you feel upset at all following the interview, I will be available to talk with you. Alternatively, the department's Consultant Clinical Psychologist, Dr Christopher Hewitt, will also be available to talk with you. For participants who decide to have a telephone interview, I will pass on the contact details of Dr Christopher Hewitt should you wish to seek further psychological support.

What are the possible advantages of taking part?

There may be no direct benefit to you from participating in this study; however the information you provide may be helping others in the future. The information that we learn from the study might help us to understand more about the things which influence how people remember and understand information given to them about their transplant, and may influence how we provide such information to BMT patients. If there are particular things that you are unable to remember during our meeting, with your consent, I would be able to

pass this onto the medical team, so that they can be sure to discuss this with you at your next appointment.

Will my taking part in this study be kept confidential?

Your Consultant Haemato-Oncologist at the Beatson will know that you are taking part in the study. However, everything that you say during our interviews will be kept strictly confidential and no-one but myself will have access to the recordings of the interviews. All interview recordings will be destroyed after being transcribed and analysis completed. Your name, or other identifying information will not appear in any reports or publication from this study.

Are there any circumstances when information shared by me during the interview would not be kept confidential?

Everything you say during the interview will be kept private. However, if you tell me anything that suggests that you or anyone else is at risk of harm, then it is my duty to share this information with other appropriate professionals.

What will happen to the results of the research study?

I will provide you with a summary of the results of the study. The final results and conclusions of the study may be published in a scientific journal and will form part of my qualification in Clinical Psychology. Your identification will not be included in any publication.

Who is organising and funding the research?

NHS Greater Glasgow & Clyde is the Sponsor for this study and there is sufficient funding available for the researcher to carry out this research.

Who has reviewed the study?

The study has been reviewed by the Department of Psychological Medicine at Glasgow University and has been reviewed by the West of Scotland Research Ethics Committee to ensure to ensure scientific and ethical conduct. The study has also received organisational approval from the Beatson West of Scotland Cancer Centre.

Contact for further information

If you have any questions or would like to discuss this with me before making your decision, you can contact me: Shehnaz Iqbal, Trainee Clinical Psychologist, Mental Health and Wellbeing, 1st floor, Administration Building, Gartnavel Royal Hospital, 1055 Great Western Road, GLASGOW G12 0XH. Also contactable by telephone : 0141 301 7324 and email: siqbal.2@research.gla.ac.uk

Can I speak with someone not directly involved in the study?

If you wish to speak with someone not directly involved in the study about any aspect of the research process then you can contact Dr Kenneth Mullen Mental Health and Wellbeing, 1st floor, Administration Building, Gartnavel Royal Hospital, 1055 Great Western Road, GLASGOW G12 0XH. Also contactable via telephone: 0141 211 3932 and email Kenneth.mullen@glasgow.ac.uk. Thank you for taking the time to read this information.

Appendix 2.7: Participant Consent Form

Factors Influencing Patient Recall and Understanding of Haemato-Oncology Consultations: An exploratory study.

Participant Consent Form

Correspondence to:

Shehnaz Iqbal

Trainee Clinical Psychologist Mental

Health and Wellbeing

1st floor, Administration Building

Gartnavel Royal Hospital

1055 Great Western Road GLASGOW

G12 0XH

FACTORS INFLUENCING PATIENT RECALL AND

UNDERSTANDING OF HAEMATO-ONCOLOGY

CONSULTATIONS

<u>**Participant Consent Form**</u>

Please put your initials in each of the boxes to show that you have read and are in agreement with the statements:

1 . I confirm that I have read and understand the information sheet (Version 2.0 date: 19/12/2012) for the above study and have had the opportunity to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected

3. I understand that the medical clinician who is involved in my care (Doctor or Nurse at the hospital) will be informed of my participation in the research

4. I understand that my medical consultation and subsequent interview, will be taped using a digital recording device, solely for the purpose of the research study as described in the Participant Information Sheet and will be kept confidential

5. I understand that quotations may be published but that all names, places and identifiers will be removed once all the information has been gathered

6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities, the University of Glasgow, or from
NHS Greater Glasgow and Clyde, where it is relevant to my taking part in this research

7. I agree to take part in the above study

Name of Participant_____**Date**_____**Signature** _____

Researcher_____**Date**_____**Signature** _____

Thank you for taking part in this study

(1 copy for participant and researcher and 1 copy for medical notes)

Appendix 2.8   Major Research Project Proposal

Factors Influencing Patient Recall and Understanding of Haemato-Oncology Consultations: An exploratory study.

Major Research Project Proposal

Correspondence to:

Shehnaz Iqbal

Trainee Clinical Psychologist

Mental Health and Wellbeing
1st floor, Administration Building
Gartnavel Royal Hospital
1055 Great Western
Road GLASGOW G12
0XH

1. Introduction

1.1 Background

Hematopoietic stem cell transplantation (HSCT) is a form of treatment used with patients diagnosed with leukaemia. Leukaemia is one of the most aggressive forms of cancer (Cancer Research UK, 2011) - categorised into *two main types*: *chronic* (<u>chronic lymphocytic leukaemia</u> (CLL) or <u>chronic myelogenous leukaemia </u>(CML)) and *acute* (<u>acute lymphoblastic leukaemia</u> (ALL) or <u>acute myelogenous leukaemia </u>(AML)) *leukaemia*. The primary aim of HSCT is to eliminate the leukaemia cells completely, allowing permanent regeneration of bone marrow by healthy and normal bone marrow cells. There are three *sources* of stem cells; 1) bone marrow 2) cord blood or 3) peripheral blood.

There are two main *types* of transplantation: *autologous* and *allogeneic*. During *autologous* transplant the patient's *own* marrow or peripheral blood stem cells are used. This is different from *allogeneic* transplant when the patient receives bone marrow or peripheral blood stem cells (PBSC) from a matched sibling or unrelated/voluntary *donor* (VUD). *Allogeneic* transplant patients will form the sample of the present study.

Stem cells for *allogeneic* transplant can be harvested from bone marrow from the donor's hip bone under general anaesthetic or taken from blood following injections of granulocyte colony stimulating factor (G-CSF[1]). The donor's blood is drawn and reserved using an apheresis machine (blood cell separator). The patient receives aggressive, high dose chemotherapy and occasionally radiotherapy to destroy any cancer cells. This is called conditioning treatment. Afterwards, the stem cells (originally sourced from the donor) are processed and transfused into the patient to restore cells of the body that have been destroyed by conditioning treatment.

HSCT is associated with a number of serious emotional and physical complications that can significantly reduce patient's quality of life, most notably graft vs. host disease (GvHD) (Gratwohl et al. 2010). GvHD is a life-threatening immune reaction whereby cells from the donor's immune system are recognized by the patient's body and rejected. Acute GvHD develops immediately after

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[1] Growth factor (G-CSF)- stimulates movement of stem cells from the bone marrow into the bloodstream

transplant and is usually managed with drugs, including steroids to further suppress the new immune system and reduce symptoms. Whilst HSCT remains a dangerous procedure, associated with potentially fatal consequences, it also offers hope of cure when other cancer treatments have been unsuccessful (Gratwohl et al. 2010). Prior to consenting to HSCT, patients attend medical consultations, during which they are informed about the potentially curative effects (e.g. chance of survival) of HSCT as well as possible life threatening risks (e.g. GvHD). At worst, patients have to accept the risk of dying as a result of HSCT and not of the disease itself (Grulke & Bailer, 2010).

1.2 Communication in Cancer Care

The National Institute of Clinical Excellence (NICE, 2003) guidelines for haematological cancers advocate patient centred care through clear and accurate dissemination of treatment options to patients, so they can make informed decisions about cancer care and treatment. The quality of this interaction can be evaluated by measuring patient's recall and understanding of information given to them during consultations (Carlson et al. 2005). Patient's recall of cancer treatment consultations has previously been defined and measured empirically (Fallowfield *et al*. 1999; Carlson *et al*., 2005; Jenkins *et al*., 2009). Although the research literature fails to provide a clear operational definition of patient understanding of cancer treatment, the concept has been measured (Jenkins *et al*. 2008).

1.3 Factors influencing doctor-patient interaction

Ley's model (1988) of effective communication emphasises the relationship between patient's memory, understanding and satisfaction on recall during medical consultations. Kessels (2003) reported that 40-80% of medical information presented by health care professionals was forgotten immediately by patients; influenced by a combination of consultant (i.e. use of medical terminology) and patient factors (i.e. emotional state and older age) including having received previous cancer treatments, which may have resulted in cognitive impairment (Friedman et al. 2009). Thus, many variables can influence doctor-patient interactions, including both patient and iatrogenic factors. The current and brief review of literature shall only consider factors intrinsic to patients that are of relevance to the present study.

1.4 Cognitive impairment

Many allogeneic transplant patients will have received chemotherapy regimens at an earlier stage in the treatment of their disease. Research demonstrates that cancer survivors who have received radiotherapy and chemotherapy can experience impaired cognition as a consequence of these

treatments (Joly et al. 2011). Asher's (2011) review of cognitive dysfunction among cancer survivors reported that individuals with acute leukemias and myleodysplastic syndrome have impairments before treatment, including deficits in memory and learning, processing speed, aspects of executive functioning and upper limb dexterity. This review also suggests that cognitive dysfunction may also be explained by anxiety, depression and fatigue which are problems commonly experienced by this population.

1.5 Anxiety

Anxiety may inhibit or facilitate recall and understanding of information given during medical consultations. Kessels (2003) explains this phenomeonon in terms of "attentional narrowing". This occurs when information or events perceived as aversive (e.g. side effects of treatment) become the primary focus of attention. This may cause anxiety and limit patient's attention towards information perceived as being less important, allowing them to "focus on" concerning aspects of information and thereby experience enhanced recall of it. Information perceived as upsetting, may cause patients to become overwhelmed and this may impact adversley upon their ability to cognitively process information they receive during consultations. Patients may believe that they lack information, consequently causing feelings of uncertainty, anxiety and depresssion (Ong, 2000). Both very high and low levels of anxiety can lead to lower recall of information with moderate levels resulting in optimal performance on tests of recall (Ley, 1988).

1.6 Depression

Patients with advanced cancer often experience strong emotions such as sadness, anxiety, and fear throughout the course of their illness (Derogatis et al. 1983) which can impair memory function (Blaney, 1986) and impact negatively upon their ability to recall information during cancer consultations (Carlson. et al 2005). Specifically, Kizilbash et al. (2002) reported that depressive symptoms (with or without anxiety) have a negative effect on immediate recall of new information and amount of acquisition but not on retrieval or retention. Given that HSCT consultations contain medical (new information) and highly emotive information, then it is plausible to assume that degree of depression will have an adverse effect on patient's recall and understanding of new information presented to them during consultation.

1.7 HSCT consultations

Whilst communication has been researched extensively within the field of oncology (Rodriguez et al. 2010), few studies have investigated communication processes that occur within HSCT consultations (Jenkins et al. 2011) and fewer still with individuals diagnosed with acute leukaemias following their consultations for HSCT (Merckaert *et al*., 2009; Grulke and Bailer, 2010; Alexander *et al*., 2012). Consultations about HSCT tend to be longer due to the complexity and amount of information which needs to be given to transplant recipients regarding treatment options, processes and long-term side- effects, giving rise to a higher frequency of giving and receiving of communication behaviours than in other settings (Alexander et al. 2012). No research to date has investigated the influence of patient factors, in particular level of cognitive ability, on patient recall and understanding of HSCT consultations.

2. Aim and objectives

2.1 Aim

To explore the recall and understanding of information given during a consultation with a Haemato- Oncologist, of patients who are due to undergo VUD transplant for (acute or chronic) leukaemia.

2.2 Objectives

Using semi-structured interviews and a qualitative approach, the study will investigate patients' recall and understanding of their HSCT consultation. This will be accomplished by:

1) Identifying how much information from the consultation is recalled accurately, as well as identifying the types of information that either tend to be recalled or not recalled

2) Having identified the key areas of information, to be given in the consultation by prior discussion with the consultant, to examine level of patients' understanding of these areas by eliciting patient's knowledge/understanding through the use of focused questions

3) In addition, to provide a context for the patients' performance, possible influences on the patients' recall and understanding of the consultation will be assessed through evaluation of patients' anxiety, depression and memory function.

3. Plan of investigation

Due to the researchers' limited knowledge of HSCT, permission was granted by the local clinical governance committee, for her to observe consultations to gain an understanding of how clinics are conducted prior to commencing the study. This was considered by the committee as service evaluation, providing that, consent was obtained from patient's and consultants, consultations were not tape-recorded and all subsequent work and the main application would be subject to full ethics application.

A coding framework (the recall and understanding interview template (RUIT)) was developed for recording and scoring agreement between information conveyed by the consultant and information recalled and understood by the patient. This task was aided by the researchers' observations of HSCT consultations prior to commencing recruitment as well as other key sources.

3.2 Sample

All first visit patient's eligible for VUD HSCT with a diagnosis of acute/chronic leukaemia and referred consecutively to the Beatson West of Scotland Cancer Centre (BWoSCC). The BWoSCC database indicates that approximately 8 AML/ALL VUD transplants patients are recruitable within a 6 month period.

3.3 Justification of sample size

Methods employed in previous research were not sufficiently comparable due to variations in sample sizes that do not consistently fulfil requirements for statistical power (Merkaert et al. 2009; Mystakidou, 2009). Within qualitative research, sample size is not predetermined; therefore power calculations are not appropriate. Contrary to quantative research which provides the best opportunity to generalize results to the population, the essence of qualitative research, is to gain an in-depth, rich and complex understanding of the meanings patients attribute to their experience from their perspective (Fagerlind et al. 2012) and in the context of the current research, provide insight into the population required to make decisions about HSCT. Instead of placing the elements of a consultation in predefined categories, using this approach, themes are established based on the data while coding

(3). Therefore purposive, convenience sampling will be used who meet selection criteria (3.4). This sampling technique means that the number of cases is not predetermined, however based on the referral rate, recruitment time-frame of participants and research design of the present study, a sample size of 8 participant's was deemed feasible.

3.4 Inclusion/Exclusion criteria

Inclusion criteria. Participants have to be;

- candidates for HSCT
- at least 18 years old
- express awareness of their diagnosis
- have English as their first language.

Exclusion criteria. Patients with;

- severe psychiatric morbidity
- substance misuse
- no capacity to give informed consent

3.5 Recruitment procedures (Figure 1)

Participants referred for HSCT to the BWoSCC between January 2013 and June 2013 and identified as meeting inclusion criteria will be sent an invitation letter with an attached 'consent to be contacted by researcher' form alongside their hospital letter for initial clinic appointment. Participants interested in taking part can return the consent form via a stamped addressed envelope to the researcher who will contact participants individually and explain the process fully. Interested participants will then be given a participant information sheet, full consent form and relevant pre-consultation questionnaires to complete on the day of their HSCT appointment. This process will be outlined in the Participant Information Sheet and in the instruction sheet included in the questionnaire pack.

3.6 Design

A cross-sectional within subjects' cohort design will be used to evaluate the objectives.

3.7 Research procedures

On the day of the patient's medical appointment, the researcher will introduce herself to the patient, explain the research procedure, obtain the informed consent form and collect the completed questionnaires. The medical consultation (approximately 1 hour), shall be digitally recorded. The digital voice recorder (DVR) will be placed in the clinic room and started prior to the participant and consultant entering the room by the researcher. Following the consultation, and once the participant leaves the clinic room; the DVR will be collected by the researcher. The researcher will then interview the participant using the RUIT in a separate clinic room. This interview will also be recorded. Every effort will be made to work around patients schedules. The option of conducting post- consultation RUIT interviews over the telephone will be given for patient's convenience and to decrease burden. Consent to record the consultation will also be sought from the individual Consultant Haemato-Oncologist. Figure 1 shows a preliminary outline of the participant's recruitment and participation in the study.

3.8 Figure 1. Flow chart of patient journey through process of recruitment

(insert flow chart)

3.9 Measures

To better understand the target population and factors that impact on their recall and understanding individually the following measures will be used:

1. Hospital Anxiety and Depression Scale (HADS, Zigmund & Snaith, 1983). A self-administered scale, containing two separable scales: depression and anxiety. The scale has 14 items in total (seven covering depression and seven covering anxiety). The maximum score for each subscale is 21. For the HADS depression subscale (HADS-D), a score of 10 is the recommended threshold for considering intervention.

2. Functional Assessment of Cancer Therapy–Cognitive Function (FACT Cog). (Wagner et al. 2005) Using a criterion of two or more times a week, individuals complete 50 items related to memory function and 4 of these items invite them to report perceptions of others i.e. "Other People Noticed Deficits".

In addition to the above measures, participants' age, gender, years of formal education, previous exposure to cancer treatments, instances of traumatic brain injury and clinically significant scores from the above self-report outcome measures will also be summarised and presented in tabular form to contextualise participants' performance. This information will be obtained from participants' casenotes which will be hand searched following ethical approval from the Beatson West of Scotland Cancer Centre Ethics Committee (BWoSCCEC).

3.10 Analysis of RUIT for HSCT Consultations

Research recommends that patients are interviewed immediately after consultations for optimal performance on tests of recall (Carlson et al. 2005), where possible, this will be followed. However, to reduce the risk of overwhelming patients, assessment of patient recall and understanding will occur individually with the researcher at a convenient time point between the first and second consultation. The RUIT will be used as a template, from which the researcher will base her semi-structured interview to compare their level of recall and understanding against established key topics. The RUIT will be used with actual participants' to identify level of concordance of what was explained/defined and what the patient correctly

understood and recollected. The questions will be open-ended to allow for participants' individual interpretation and exploration of the key topics of information transmitted by the consultant during consultation. These will be followed up by targeted questions to obtain further information about key topics. The semi-structured format is considered appropriate to explore individuals' perceptions of doctor patient communication and the factors influencing it (Carlson et al., 2005). Patient interviews will take between 20-30 minutes. The interview will be digitally recorded, uploaded onto the laptop and transcribed verbatim, anonymising any references to person or place.

Directed Content analysis will be used to code and analyse recall and understanding of the communication from the consultation (Carlson et al., 2005) using pre-determined categories from the RUIT. This will involve coding and analysing the level of concordance between information given by the Consultant during consultation and individual patients' recall and understanding of this, using the RUIT. Coding will be conducted manually. Although coding may begin immediately due to coding schemes having been established (Hsieh and Shannon, 2005) through the RUIT, the researcher will begin to identify and categorise all instances of recall and understanding, by reading the transcript and highlighting all the text that on first impression appears to represent a unit of recall and/or understanding. This is to capture all the possible occurrences of the phenomenon and may increase trustworthiness of the coding framework (Hsieh and Shannon, 2005). The next step in analysis will be to code all highlighted passages using predetermined codes from the RUIT. Any text that may not be categorised with the initial coding scheme will be given a new code. Participants will also be asked if they have consulted any other resources (e.g. carer/internet regarding information), and if so, what the content of this was to account for any additional sources of biases. To limit researcher subjectivity and bias, the coded framework and content of each participant's interview will be reviewed by the academic supervisor in addition to the researcher themselves.

4. Settings and Equipment

Setting:
BWoSCC outpatient clinic.

Equipment:
Outcome measures, recall interview schedule, envelopes, password encrypted laptop, DVR, digital recording equipment (x2) and telephone recording device for telephone interviews.

4.1 Health and safety issues

Researcher safety issues:

It is not anticipated that there will be any risks to the researcher whilst conducting the study. Meetings with participants will be conducted at BWoSCC, within staffed areas and standard working hours. The researcher will engage in supervision with Field Supervisor, Dr Christopher Hewitt as a routine to ensure any emotional distress is managed effectively and minimised.

Participant safety issues:

The researcher will do her best to provide a comfortable setting for participants during research interviews. Participants may become distressed or fatigued as a consequence or during the process of discussing distressing information. The researcher is a trainee clinical psychologist, trained to ensure distress is managed sensitively and supportively. To ensure distress is minimised, participants will be reminded that before commencing interviewing they can stop at any time or choose not to answer any of the questions. They will also be given the opportunity of break/stop the interview. Should participants become distressed this will be managed to the best of the trainee's ability and the option of further psychological support will be given in the form of Clinical Psychology provision based within the BWoSCC. Permission will be sought from the patient that should the researcher become aware of any aspects of the consultation that have not been understood, she can give a list of the problem areas to their consultant so that the consultant can address them with the patient at their next appointment.

5. Ethical issues

Ethical approval will be sought from the West of Scotland Research Ethics Committee having obtained approval from the Beatson Clinical Trials Executive Committee. A patient information leaflet will be sent out indicating that participation is entirely voluntary. Refusal to take part in the study will in no way impact ongoing medical care. Participants who do not wish to take part in the study do not need to return the consent form. A reminder of confidentiality and the right to withdraw will remain open throughout the study. The Principal Investigator will ensure that the study will be carried out in accordance with the ethical principles in the Research Governance Framework for Health and Community Care (2006) and applicable legal and regulatory requirements.

5.1 Informed consent

Patients will be provided with both verbal and written information regarding the study. Written information will outline the reasons for the study and precautions regarding protection of patient's confidentiality. Should risk arise during the study, participants' GP/consultant will be informed. Any contact with GP/consultant will be discussed with the participant beforehand

and the participant information sheet will outline this procedure for potential participants.

6. Data protection

Data will be stored electronically on an NHS password encrypted University laptop. All paperwork will be stored in a locked filing cabinet at the University. Personal identifiers will be removed from data and a unique code assigned to each patient.

6.1 Research conduct

Further discussion of research as well as areas of concern can also be addressed by research supervisors should patients/carers wish as information sheets will provide their contact details.

6.2 Financial and indemnity issues

Sufficient funding is available for the researcher to carry out the research. NHS employed researchers are covered for negligent harm through the NHS Clinical Negligence and Other Risks Scheme (CNORIS) indemnity scheme.

7. Practical applications

To identify factors that influence recall and understanding of patient consultations and consider mediums to facilitate patient recall thus enhance decision making about treatment.

8. Planned dissemination of research results

The results of the study will be written up and submitted to the West of Scotland Doctorate in Clinical Psychology Programme for assessment purposes. It is hoped that the final results and conclusions of the study will be published in a scientific journal.

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Appendix 2.9 Semi-Structured Interview Schedule

FACTORS INFLUENCING PATIENT RECALL AND UNDERSTANDING

OF HAEMATO-ONCOLOGY CONSULTATIONS

<u>Recall and Understanding Interview Template (RUIT)</u>

Researcher introduces self to the patient and asks if they would be prepared to answer a few questions about their experience of their consultation and the information they were given by the consultant.

If yes: ask the patient if they have time to do this immediately.

If yes, but not now: thank the participant for their time and confirm contact details to arrange an alternative date/time prior to their next appointment at the Beatson.

If no: thank the participant for their time.

Immediately prior to commencing the recall and understanding interview, say to the patient "I am going to ask you some questions about how much you can remember from your consultation from (say date). Is that okay with you? We are asking you these questions to try and find out what patients remember and understand about what the doctor said to them about transplant. This is not a test of your memory but rather to learn more about factors that might influence how much information you can remember, and the types of information that patients tend to forget after their hospital consultations about bone marrow transplant (BMT). This type of research might help to identify factors that influence recall and understanding of medical information, and help us to think of ways we could help patients gain as much as possible from their appointments."

The researcher may also explain about confidentiality and limits to this at this point. The researcher will advise the patient that they can take a break at any time throughout the interview should they feel unable to continue for whatever reason. They may also recommence the interview and/or reschedule at a more convenient time if

their distress is such that they do not wish to continue. They will also be reminded of their right to withdraw from participation in the study at any point and that this will in no way effect their ongoing treatment. Patients will also be reminded of the availability of further psychological support via the Clinical Psychology Service at the Beatson should this be required.

Ask the patient if they have any information about cancer or their summaries near them and if they do ask if they could put them out of sight.

Note: where a patient asks for further information e.g. if they remember the doctor said something but cannot remember the details, explain to the patient that I am unable to give this kind of information, because I am not a member of the bone marrow transplant team and do not have a medical background, so will be unable to answer any questions about their care and treatment. Let them know that I will take a note of their questions/comments and should they be agreeable, pass them onto their consultant who will be able to answer their questions.

Part 1: Spontaneous Recall

Say to the patient "can you talk me through everything you remember the doctor saying to you during your consultation (date)?"

When the patient stops talking, say "can you remember anything else?" and continue to ask this until the patient cannot remember any further information and move onto the prompted recall section.

Can you let me know about what, if any, sources of information you have looked at since your initial consultation? What did you learn about transplant/your illness?

Part 2: Prompted Recall

Once the patient has given all the information that they are able to remember in the spontaneous recall section say to the patient:

"I am now going to ask you some more specific questions about what the doctor said to see if that helps you to remember anything you haven't mentioned so far. Is that ok? You do not have to repeat anything you have already said, but it does not matter if you do. **Not all the questions will necessarily apply to you, but I am going to ask all the questions I have so don't worry if you answer no to any of the questions.**"

There are questions below each of the categories and suggested prompts. The prompts are deliberately vague to avoid leading the patient and are often just a rewording of the original question. The prompts should be used until the patient cannot provide any further information. in any given category.

There are also examples of possible responses under each category. These are examples only and the lists are not exhaustive. They are to give an idea of the types of information that could fit into each category. For some categories there will only be one possible response (e.g. type of transplant) and for others there are many possible responses (e.g. side-effects). In addition, some of the categories will have fairly standard responses (e.g. process of transplant) whereas other categories will be more individual to the patient (e.g. practicalities of treatments).

We do not need to know all the possible answers in any given category because for each patient we will have all possible correct answers from the consultation recording.

Categories of information

1. Information about the patient's current/past health status - cancer (e.g. type/size)

Did the consultant talk with you about your health condition/illness? What do you remember the doctor telling you about your health condition/illness?

If yes: where the patient remembers details: ask for further information e.g. do you know what that means? Can you remember anything else?

Proceed to category 2

If no: Where the patient does not remember any details: prompt with e.g. did the doctor mention anything about what kind of cancer you have, for example

Examples:

1. Type

- Leukaemia – AML, ALL, CML , CLL$_{142}$

- Lymphoma etc etc

2. Stage

- Progression of cancer

- Protein status

- Grade

2. **Treatment optionsDo you remember the doctor telling you anything about the treatment(s) that are available to you for the cancer? Do you know what treatment the consultant has recommended/considering you for?**

If yes: ask for further information e.g. "what is that?" "Did the doctor mention anything else?"

If no: we would expect patients to know at least the main treatment they are going to have, however if the patient says they do not know ask "are you coming back to the hospital? Do you know why you are coming back?

Examples:

a) Transplant

- Bone marrow transplant a) from voluntary donor (VUD) b) from sibling autologous (auto)

b) Conditioning treatment (radiotherapy and chemotherapy)

c) Other

- Cyclosporine
- Other immunosuppressant's/anti-viral drugs
- Childhood vaccinations

3. Aims of treatment

Do you remember what (if anything) the doctor told you about the aims of this treatment? Do you know what other treatment (s) you will be given as well as transplant?

If yes: do you know what that means? Did the doctor say anything else about the aims

of these treatments?

If no: do you remember if the doctor said why they suggested that you to consider this treatment?

Note if the patient answered category 2 with more than one treatment ask: did the doctor mention anything about the aims of (other treatments)

Examples
a) Conditioning treatment

- remove any remaining cancerous cells

b) Transplant

- give the body a new immune system

- cure the cancer

- reduce the chance of recurrence

4. Side effects of treatment

Do you remember the doctor telling you anything about possible side effects of having this treatment?

If yes: can you remember if the doctor mentioned any other side effects?

If no: do you remember if the doctor said the treatment might have any effects on you that were not to do with the cancer?

Note: if the patient answered category 2 with more than one treatment and answers this category referring to only one treatment ask: did the doctor mention anything about possible side effects of (other treatment)?

Examples of possible answers:

1. Conditioning treatment: diarrhoea, fever, hair loss, nausea/vomiting, recovery time, mucositis, infection risk, cataracts, infertility, reduced white blood cell count, thyroid, loss of libido 2nd cancers, depression, extreme tiredness, lack of concentration, focus

2. Transplant: diarrhoea, fever, hair loss, nausea/vomiting, graft failure/ Chronic/acute Graft vs. host disease (GvHD) recovery time, mucositis, infection risk, cataracts, infertility, reduced white blood cell count, thyroid, loss of libido, increased risk of 2nd cancers, depression, extreme tiredness, lack of concentration, focus

3. Immuno suppressants/vaccines/anti-biotic

5. Graft vs. Hosts Disease (GvHD)

Do you remember if your consultant spoke with you about a significant post transplant risk of graft vs. host's disease? Did they talk about the (2 main – acute/chronic) types of GvHD?

If yes: ask for further information

If no: prompt further e.g. did the consultant mention anything about the possibility of you contracting illness/infection after the transplant procedure? Do you remember the doctor telling you there are things you should or should not be doing? Why was that?

If the patient answered category 2 with more than one treatment and answers this category referring to only one treatment ask "did the doctor mention anything about what life might be like for you and your family after the transplant?"

Examples:

- It's like the new immune system that rejects your body

6. Prognostic discussion related to risk of mortality/chances of cure

Do you remember the consultant telling you anything about your chances of cure/survival with and without this (these) treatment (s)?

Examples:

- % cure/survival

- Recovery time , to be realistic and based on your age, previous illness, health you have X percentage of survival/cure

- This tends to be an aggressive treatment and there is 50% chance of mortality in the first 3 months

7. Impact of treatment on quality of life

Do you remember if your consultant spoke with you about your quality of life/course of recovery? Did he/she speak with you about the level of support required after the operation?

If yes: ask for further information

If no: prompt further e.g. Do you remember the doctor telling you there are things you should or should not be doing after transplant? Are you considering going back to work, do you know how long that will take? Why was that?

Note: the responses to this question might be more individual e.g. quality of life may depend on things like type of job, level of family support etc.

If the patient answered category 2 with more than one treatment and answers this category referring to only one treatment ask "did the doctor mention anything about what life might be like for you and your family after the transplant?

Examples:

- Support with hospital visits/ transplant after care

- Current living arrangements

- Financial matters

8. Practical issues regarding treatment (e.g. when, where, how often, etc)

Do you remember if the doctor told you anything about the practicalities of having this (these) treatment (s)? Did they mention anything about how they administer the treatment?

How long it would take? Whether there are things you should or should not do? Or anything else like that?

If yes: ask for further information

If no: prompt further e.g. are you coming back to the hospital, do you know how often you will have to come back and why? Do you remember the doctor telling you there are things you should or should not be doing? Why was that?

Note: the responses to this question might be more individual e.g. practicalities may include things like recovery duration, return to work etc.

If the patient answered category 2 with more than one treatment and answers this category referring to only one treatment ask "did the doctor mention anything about the practicalities of having (other treatment)?

Examples

1. Chemotherapy – treatment

- Length of treatment

- No of visits

2. Radiotherapy – treatment

9. Role in decision making and treatment recommendations

Did you feel you were/are able to make an informed decision about treatment based on the information you were given?

If yes: ask for more information

If no: ask did you receive information about treatment that was enough to help you decide

if transplant is for you or not?

10. Other tests/treatments

Do you remember if the doctor mentioned anything about other possible treatments or trials that you may be eligible for?

If yes: ask for more information

If no: say to the patient are you aware of options other than transplant available here at the hospital or elsewhere?

11. Next steps

Did the consultant make you aware of what tests you need to complete? Did they talk about the next steps for you in this process of considering transplant?

If yes: ask for more information

If no: usually we would expect patients to know that they are going for further tests or have completed them e.g. liver function. However, if the patient cannot remember then ask about what tests have already been completed at the Beatson.

Examples:

- I am going/been for liver, kidney function/blood tests

- I am going to have a look around the unit

Ending

Thank the participant for their time and effort during the interview. Emphasise that they can receive the results of the study if they so wish. Ask them for their preferred method of contact for this information. Participant information sheet has contact details on them should they wish to raise anything about the study with Researcher.

Appendix 3: Recall and Understanding Information Template (RUIT) Adjustments

Revision. Delete this category as it is information requested by the doctor from the patient, not given to them, therefore cannot be evaluated.

~~1.information pertaining to patient's current/past health and well being~~
~~Clarification of the following:~~

~~a.   what the patient understands about their illness~~

~~b.   purpose of consultation~~

~~c.type and stage of illness~~

~~d.how the patient has responded to previous treatment e.g. remission status~~

~~e.   medical history – including any current medications~~

~~f.what is the patient's current health/dental status – including alcohol, smoking and~~
   ~~exercise~~

~~g.current employment arrangements~~

~~h.home situation, availability of home and social supports~~

~~2.~~ Treatment
Explanation of
process:

a. indications for VUD transplant – suitability of illness type/stage, age, donor availability, disease in remission (BMA), fitness.

b. How is a VUD transplant different from previous treatments may have received?

c. Tests required pre-transplant and reasons for these – heart, lung, kidney, liver

d. Finding a suitable matched donor, VUD or sibling

e. Notice period for donor. Likely transplant dates

f. Stem cell harvesting – how this happens, how much is needed

g. Conditioning treatments – reduced intentsity/Myeloblative; what agents are used, over what period of time

h. What happens – IV transfusion of cells through Hickman line

i. Anticipated length of hospital admission – indications of when suitable for discharge

~~3.~~ Aims of treatment
   a. explanation of purpose and intention of transplant

4. side-effects of treatment

Acute effects

a. what to expect – week 1, weeks 2-3, week 4-5
including following: high temperature, rash, rigors, mucosistis, stomach/abdominal pain, diarrohea, nausea/vomiting, fatigue, hair loss, reduced concentration/memory, increased infection risk

Revision. Delete categories 4c & 4D as it this is covered in the remainder of section 4.

b. side-effects of steroids – lose muscle, gain fat, increased BP
etc c. side effects of immune-suppressive therapy
d.management of side effects
e. estimation of length of time takes for immune system to recover
f. risk of complications diminishing over
time Late effects

g. endocrine, cardio-vascular, secondary cancers, fertility, loss of libido, cataracts
h. how these are screened for and managed – i.e. late effects clinic
i. preventative behaviours – stop smoking, high factor sun protection, bowel screening

5. Graft vs. Host Disease (GvHD)
Acute GvHD

a. what is it/why does it happen?
b. Grading
c. Symptoms – skin, liver, gut, appetite etc
d. Chances of acquiring acute GvHD – mild, moderate, severe
e. How this is prevented/managed
f. Implications of GvHD
g. Graft vs. Leukaemia Effect – explanation and implications

Chronic GvHD

h. symptoms
i. management
j. prognostic discussion

150

establish what information the patient requires

    k.   treatment related mortality

    l.   relapse

    m. disease free survival

    n.   estimation of morbidity/mortality without transplant

    6. impact of treatment of quality of life

a. physical **This item is covered in topics 2 -5.**

    b. psychological

    c. social

    d. financial/vocational

7. practical issues

a. named consultant/team approach

b. clean environment – issues around visitors, young children, single room, infection control – aprons, hand gel

c. relative overnight accommodation

d. transport

e. donor lymphocyte infusion

f. long-term anti-microbial therapy

g. change of blood group

h. re-immunisation

i. sperm banking

j. possible need for re admission

k. friends of the Beatson

l. outpatient follow up arrangements

m. support needs post discharge

8. Next steps

a. consent form – read over

b. have a look around the unit

c. read over booklet before next appointment

d. take bloods

Appendix 3.1: Participant coding sheet

Participant 2 Coding sheet Coder: Shehnaz

Iqbal Test: 1

Coding Key: 2=complete 1a=partial

recall 1b=distorted recall 0a=omission

0b=fabrication/intrusion

1	Treatment	Notes	Code
A			
B			
C			
D			
E			

F			
G			
H			
I			

2	Transplant aims		
A			

3	Side effects		
A			
B			
C			
D			
E			
F			

G			
H			
I			

4	GvHD		
A			
B			
C			
D			
E			
F			
G			
H			

149

I			

J			
K			
L			

5	Prognostic discussion		
A			
B			
C			
D			

6	Qol		
A			
B			
C			

D			

E			
F			
G			
H			

7	Practical issues		
A			
B			
C			
D			
E			
F			
G			
H			

I			

J			
K			
L			
M			

8	Next steps		
A			
B			
C			
D			

Additional relevant comments

Appendix 3.2 Coded sheet

Coding Key: 2=complete

1a=partial   recall

1b=distorted   recall

0a=omission

0b=fabrication/intrusion

Phase 1: content analysed & grouped according to 9 RUIT topics	*Phase 2: separation of patient and consultant data into RUIT categories*	*Patient*	*Consultant*	*Phase 3: coding & reaching agreement*
Treatment	1			Code
Patient accurately recalled indications for VUD transplant; suitability, donor availability and requirement of remission	A	There are 3 different factors that would be whether or not we can get my Leukaemia into remission it wont get a transplant until its in **remission** so what i will be doing is next week a will be getting different chemo therapy to try and get it into remission if that is the case then i would have to get a **suitable donor** from somewhere that would match ma body and then the treatment would be **more aggressive than the chemotherapy**. i will have to get the chemo from my own hospital and its only if i go into remission that a will get a transplant em.	said before a **suitable donor**, **remission**, fitness to take the treatment.	2 – all 3 coders agreed on level of concordance

| Patient able to discriminate how a VU transplant is different from previous treatments | B | Can have a transplant but that would only be on condition of the...as he said before a suitable donor, | not as straightforward as recovering from chemo there is the potential for a lot of hiccups along the | 0a̶ 2 – recoded & agreement reached on complete recall thereon, as participant able to |

they have had		remission, fitness to take the treatment. The other option is more chemo that would put it into remission for about a year or more but it wouldn't offer a cure long term.	way. A transplant can cure the L where the chemo couldn't. Issue with transplant is that it is a demanding process to go through in some ways more demanding than chemo you had already.	distinguish that transplant has the potential to cure the Leukemia, whereas chemotherapy wouldn't in the long term.
Tests required pre transplant and reasons for these	C		Your fit enough for a transplant if all tests looked okay, heart lung and kidneys. You would see irregularity of the liver or it might be enlarged because drinking might have caused some damage but no evidence of that in any of your blood tests. That can be done in hospital for your next lot of chemo	0a – participant omitted, when asked, information pertaining to tests required pre transplant and reasons for these.

Finding a suitable matched donor, sibling or VUD	D	If I went into remission, then I would have to get a suitable donor from somewhere that would match ma body and then the treatment would be more aggressive than chemotherapy	We don't yet have a donor but there are a number of possibilities. There are enough potential donors there tat we could find you a good match. Your disease at the time of transplant would need to be better contolled, give you different treatment to bring you back into remission. In terms of	1a – the participant partially recalled, as they identified a VUD transplant would be necessary, the intensity of transplant and suitability of the donor but not significance of matching in relation to the immune system and possible

			matching we have to find a donor that matches your immune system as closely as possible. Even if there was a brother or sister that was a match there would still be lots of differences between the immune system s and certainly when you are using an unrelated donor there's likely to be even more differences . The only immune system that would be identical to you would be an identical twin. There will always be differences there and sometimes they will be recognised sometimes not	rejection.
Notice period for donor. Likely transplant dates	E	I wont get a transplant until its (leukemia) in remission. So what I will be doing next week is trying a different chemo therapy to try and get it into remission	In an ideal world we would want to do is wait until your blood counts recover and look into your bone arrow. Get your chemo, get time at home before bringing you in for transplant	2 – consultant did not give exact time frames as participant required chemotherapy for remission before specific dates can be given for transplant.

| Stem cell harvesting | F | | gonna be half a litre can't remember what he said but it was quite a considerable amount it wasn't just little | When you get a bone marrow sample taken normally take a few ml of BM. Need to collect half a | 2 – participant able to identify how this happens and how much is needed. Whilst growth factor use |

		samples like a few millitres as they had been taken so i wonder that's what they can do if the stem cell are there with the whatever it is the immune system of the host donor then em it will grow itself basically so they don't need to remove so much from the donor em	litre of BM that can be quite tricky sometimes it involves the donor getting an anaesthetic. The bone marrow being collected from lots of points in their pelvis ____	is mentioned it was felt by the coders that the information recalled was sufficient to warrant a score of 2.
Conditioning treatments (e.g. chemotherapy)	G	it's another course of chemotherapy. Okay. But a take it won't be so aggressive so i wouldn't recover from it. Okay. . pre treatment would kill off all your immune system so that the stem cell transfusion would have some of the anti bodies and some of the what you call it system immune system from the donor so that would come into my system	You get prepared firstly normally over 7-8 days of chemotherapy similar to that, you will get next week, wont be exactly the same will be a few differences. The current chemotherapy you get is capped at a a level that will allow the bone marrow to recover. For transplant it is at a higher level cause don't want bone marrow to recover after treatment	2 participant recalled information completely, indicating the need for conditioning treatment and the purpose. All coders agreed on this.

What happens – IV transfusion of cells through Hickman line	H	Would just be like a blood transfusion okay. Its however many litres or half a litre or something eh liquid just actually administered via	Few bags of cells that go up in a drip through a Hickman line to your BM. So there's no injection or operation the transplant is really a transfusion. These stem	2. As above

		intravenous transfusion like blood transfusion but eh how long would it take did they say.... aw its like i don't know about transplant but the chemo lasts for 10 days right. So whatever pre treatment it was like very aggressive chemo would get here to kill off everything so that host em stem cell transfusion could be thingied into a blank sort of canvas as it were. So that you wouldn't have any of your own bone marrow or you wouldn't have any leukaemia cells, blood cells or anything would be all the new stuff put in. So that's what would happen for the first few	cells find their way to your bone marrow and make new blood cells for you.	
Anticipated length of hospital admission – indications of when suitable for discharge	I	in hospital like from 3-6 weeks	You will be ready get home 4-6 weeks after transplant.	2 1a Participant partially recalled this information

Appendix 3.3: Recall and understanding information template (RUIT) coding guidelines

The coding procedure

Transcripts ought to be coded by 2 or more coders, enlisting the support of either the field or researcher supervisor or principal investigator of this study. It is intended that coders follow these guidelines to enhance the reliability of their findings. However, when coding it is important to bear in mind that absence of similar findings does not provide grounds for refutation, particularly when consistencies in the application of codes across data sets exits, which arguable can contribute to increased confidence in the findings of the study. The guidelines for coding are organised so that coders can gain confidence and reliability as they gain independence.

1. The lead coder will provide coded examples of each RUIT topic.
2. Both sets of transcripts ought to be read between 3-4 times (Figure 1). Enlist the help of an additional skilled researcher/coder to audit each consultation and interview transcript to ensure accuracy.
3. Learn the RUIT topics, corresponding items, and codes through discussion with a member of the research team.
4. To allow data to be compared, create 2 columns corresponding to each RUIT category, into which consultant information and patient recall and understanding of the same information can be separated.
5. RUIT topic categories and associated items can be identified on the consultation transcripts on a line by line basis and by indicating RUIT topic number in the margins of the transcripts (see appendix 2.2). Similarly RUIT topic numbers were also applied to the interview transcripts.

Figure 1. Example of sentence by sentence coding from consultation

Consultation transcript text	Interview transcript text

*Consultant: From then on its a case of dealing with effects of treatment and dealing with effects of the transplant. Idea of the chemo is to suppress your Immune System and Bone Marrow it will stop your Bone Marrow (BM) working and will **4e**take 2/3 weeks for the new BM to be working during that time your blood counts going to drop down to very low levels so your not going to have white cells in your blood and those are important for protecting you from infection. Platelets help your blood to clot. So you won't have any platelets so **4c**you will be at increased risk of infection and you're going to be at increased risk of bleeding. You might need blood transfusions and so you're very vulnerable and so you're looked after in a room in the transplant unit*	**4**P: He said there would be risk of infection more so in first 3 months. But longer you go on less chance of infection. You could feel dizzy; vomiting catch coughs colds and all these kinds of things. You're going to feel ill more immediately after. Score=1b
*specially designed to protect you from infection. During the time from transplant – no problem wondering around ward but wouldn't want you leaving the ward cause your in an **8b**environment that's designed to protect you and keep you safe no problem getting visitors as long as they don't have coughs and colds or upset tummies.*	

Recall and Understanding codes

2 = complete; 1a = partial recall, 1b distorted recall; 0a = omission, 0b = fabrication/intrusion

Figure 2. Example coding sheet

Participant 1 Coding sheet

Coder: Researcher 1

Test: 1

Coding Key:

2=complete

1a=partial recall

1b=distorted recall

0a=omission

0b=fabrication/intrusion

1	Current/past well-being	Notes	Code
A			
B			
C			
D			
E			
F			
G			
H			

2	Treatment	Notes	Code
A			
B			
C			
D			
E			
F			
G			
H			
I			

6. Patient data can be compared with consultant's data to establish level of agreement. In the original coding and analysis level of recall is established by counting the "bits" of information given by the consultant under each topic and the corresponding "bits" of information recalled by the patient. Apply the following codes to evaluate level of both recall and understanding. To differentiate between errors of commission (e.g. misunderstandings) and errors of omission, sub-codes were devised from the following 3 level structures: 2 = complete; 1a = partial recall, 1b distorted recall; 0a = omission, 0b = fabrication/intrusion

7. Subsequent to data preparation and organisation onto the coding sheet, create an additional column (see below).

Figure 3. Example coding excerpt from coding sheet

2. *Explanation of treatment*	*Category*	*Patient transcript*	*Consultant transcript*	*Code assigned*
Patient able to discriminate how a HSCT transplant is different from previous treatments they have had	B	Can have a transplant but that would only be on condition of the...as he said before a suitable donor, remission, fitness to take the treatment. The other option is more chemo that would put it into remission for about a year or more but it wouldn't offer a cure long term.	not as straightforward as recovering from chemo there is the potential for a lot of hiccups along the way. A transplant can cure the leukemia where the chemo couldn't. Issue with transplant is that it is a demanding process to go through in some ways more demanding than chemo you had already.	0a—2 – recoded & agreement reached on complete recall thereon, as participant able to distinguish that transplant has the potential to cure the Leukemia, whereas chemotherapy wouldn't in the long term.

8. Figure 3 shows how the coding system can be applied in practice. Researchers ought to create their own examples of each segment and then review precoded conversations against each RUIT topic to ensure that coders capture level of recall and understanding regarding a topic and associated items.

9. Coders ought to 'team-code', reading through transcripts together and recording the presence of topics, associated items and level of recall and understanding. At this point coders must decide if they are establishing level of recall and understanding based on

verbatim recall or if 'getting the gist' is enough. Coders ought to make field notes available, where necessary, to maintain an audit trail.

10. Finally, each coder should code an individual consultation and participant transcript, and this should be reviewed by the lead coder on a weekly basis.

Appendix 3.4 Inter-rater agreement by RUIT category and associated items

Treatment – explanation of process	a) Indications for VUD transplant	b) Difference between VUD and previous treatment	c) Medical tests required prior to transplant	d) Finding suitable donor	e) Notice and transplant dates	f) Stem cell harvesting	g) conditioning treatment	h) IV transfusion	i) Length of hospital stay				
0.67	0.68	1.0	1.0	0.67	0.67	1.0	1.0	0.545	1.0				
Aims of treatment	**0.55**												
Side effects of treatment	What to expect weeks 1-5	Side effects of steroids	Estimation of length recovery time for immune system	Risk of compications diminishing over time	Late effects	How these are manage	Preventative behaivours						
0.95	1.0	1.0	1.0	0.61	1.0	1.0	1.0						
Graft vs host disease	What this is	Grading	Symptoms	Possibility of acquiring GvHD	Management of GvHD	Implications of GvHD	Graft vs leukemia effect	Chronic symptoms	Management				
0.876	0.67	1.0	1.0	1.0	1.0	1.0	0.54	0.54	0.54				

Prognostic discussion	Treatment mortalit	Relapse	Disease free survival										

	y												
0.829	0.428	1.0	1.0										
Impact of treatment on QoL	Psychological	Social	Financial/vocational										
0.815	1.0	1.0	0.642										
Practical issues	Named consultant/team approach	Clean environment	Relative overnight accommodation	Transport	Donor lymphocyte infusion	Long term anti microbial therapy	Change of blood group	Reimmunisation	Sperm banking	Need for readmission	Friends of beatson	Outpatient follow up	Support needs discharge
0.95	0.565	0.736	1.0	1.0	1.0	1.0	1.0	1.0		1.0	1.0	1.0	1.0
Next steps	Consent form	Unit tour	Booklet	Take bloods									
1.0	1.0	1.0	1.0	1.0									