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Advancing Knowledge for Haemato-Oncology Nursing Practice

A project submitted to Middlesex University in partial fulfilment of the requirements for the degree of Doctor of Professional Studies in Health

Margaret Grundy

School of Health and Social Sciences
Middlesex University

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ABSTRACT

Nurses working in haemato-oncology require specialised knowledge and yet, formal education programmes and textbooks devoted to the speciality are limited. In advancing knowledge for haemato-oncology nursing practice this project endeavours to develop, synthesise, organise and disseminate available evidence making it more accessible to practising nurses. The project consists of two inter-related parts: reflection on, and critique of, the development and editing of the second edition of a nursing textbook and a Delphi study of research priorities in haemato-oncology nursing included as a chapter of the textbook.

In aiming to expand and advance the knowledge base for nurses working in haemato-oncology the concept of knowledge, ways of acquiring knowledge and types of nursing knowledge are explored and critically analysed. A textbook is mainly a source of empirical knowledge but ways of encouraging the development of other forms of relevant knowledge are discussed in relation to the format of the textbook. Critical reflection on the development of the textbook is also undertaken to determine usefulness and value.

Development of the first edition of the textbook and analysis of existing literature in haemato-oncology nursing highlighted the paucity of research informing the speciality. This provided the incentive to undertake the Delphi study. Round 1 generated a wide range of research topics, subsequently used to develop the questionnaire for round 2. Round 2 results demonstrated close clustering and little discrimination between research topics. Round 3 was therefore undertaken to increase the reliability and credibility of results and further discriminate between research priorities. Results from rounds 2 and 3 were remarkably consistent with several strong research themes emerging. These themes provide the foundations for the development of a research strategy with the potential to further advance knowledge for haemato-oncology nursing practice.

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CHAPTER 1: INTRODUCTION

The doctoral project entitled: 'Advancing knowledge in haemato-oncology nursing practice' continues the overall doctoral theme of 'advancing knowledge for cancer nursing practice' but focuses on haemato-oncology a sub-speciality of oncology nursing. The project consists of two inter-related parts: reflection on, and critique of, the development and editing of the second edition of a nursing textbook and a Delphi study of research priorities in haemato-oncology nursing included as a chapter within the textbook.

Rationale and Background for the Project

Haematological cancers account for a small proportion of cancers (Cancer Research Campaign, 2004). They are, however, complex conditions that affect all aspects of an individual's life. Many similarities exist between cancer and haemato-oncology nursing practice as both are concerned with meeting the needs of individuals with malignant disease. Individuals with haematological cancers receive more aggressive and intensive treatment regimens than those with solid tumours particularly haemopoietic stem cell transplantation (HSCT) previously known as bone marrow transplant (BMT). Consequently, side-effects tend to be more severe with greater bone marrow suppression and the associated life-threatening risks of infection and haemorrhage. Individuals also tend to spend longer periods of time in hospital than most other cancer patients (McGrath, 2000; Grundy, 2006a). HSCT, although a life-saving procedure, presents numerous life-threatening and long term toxicities that impact on all aspects of an individual's life and their role within the family and society. Family members also have care needs especially if they act as donors for their ill relative. These issues combined with increasing numbers of individuals surviving haematological cancers (Cancer Research UK (CRUK), 2007) emphasise the differences between the needs of individuals with haematological cancers and those of individuals with other forms of cancer. Research determining the particular needs of this patient group and the effectiveness of nursing interventions is therefore imperative.

Nurses working in haemato-oncology require knowledge of disease processes, treatments and their side-effects and the specialist nursing issues relevant to caring for this group of patients. Formal education programmes in the speciality are limited and until relatively recently no British nursing textbooks were devoted to the speciality. Cancer nursing texts contain relevant information but are often not specific or detailed enough in relation to haematological cancers. Medical textbooks are also available but their depth and complexity daunts many nurses. A limited number of American nursing textbooks focusing on specific aspects of haemato-oncology such as HSCT also exist. It is acknowledged that practising nurses need to use a range of resources to update and advance their knowledge. It is, however, also well recognised that busy nurses frequently do not have much time to access, read and interpret available information (Droogan & Cullum, 1998; Sleep & Clark, 1999; Thompson et al, 2001; Evans & Pearson, 2001). A textbook that assimilates, interprets, synthesises and organises the most relevant, up-to-date information on the haematological cancers making it accessible to practising nurses was therefore deemed to be important.

In 1996 as Chair of the Royal College of Nursing (RCN) Haematology and Bone Marrow Transplant Forum I led and developed a proposal for the first British nursing textbook in the speciality, developed and edited the text and wrote two chapters. Published in 2000 the book (Grundy, 2000) has proved to be hugely popular and has been reprinted four times. Feedback from critical reviews and personally from both leaders in the speciality and practising nurses has been extremely positive suggesting that the book is a significant source of knowledge for practice

The pace of change in haemato-oncology is, however, rapid. Nurses need to continually update their knowledge to keep pace with new treatments and the care individuals and their families require. In 2003 I was approached to develop the second edition of the book which forms the basis of this project. In editing the first edition I became aware that many aspects of haemato-oncology nursing lacked a robust evidence base to underpin practice. This is congruent with many areas of cancer nursing (Richardson et al, 2001). Deficits in evidence and research priorities do, however, need to be identified to generate new knowledge to support practice.

In addressing the paucity of a robust evidence base I committed to conducting a Delphi study to identify research priorities when the second edition of the textbook was proposed. The study formed a chapter in the book and I also managed the development process, edited the text and co-authored a further chapter. Including the Delphi study in the book links dissemination of existing knowledge through production of a textbook to the creation of new knowledge through identification of research priorities. This combination of assimilating and disseminating existing knowledge and generating new knowledge is seen as vital in advancing knowledge for haemato-oncology nursing practice. It also fulfils doctoral level requirements for different applications and creation of new knowledge.

Advancing knowledge for practice will contribute to my own personal and professional development and knowledge thereby supporting achievement of doctoral level capabilities. It is anticipated that the many valuable lessons learned through editing the first edition of the textbook including my knowledge and skills in editing and writing for publication will be further honed through managing the development and editing of this second edition. Experience in editing the first edition generated an awareness of the need to keep in regular communication with authors and the need for clear and comprehensive feedback on drafts. Furthermore, topics encompassed in new chapters of the second edition require to be researched to ensure appropriate content and accuracy thereby developing my own personal knowledge of the subject area.

Leadership skills are also required in taking this project forward. Despite support from my employers this project will largely be taken forward in my own time. This will require drive, commitment, persistence, energy, engagement and collaboration with others; all recognised attributes of leadership (Zaleznik, 2004; Alimo-Metcalfe & Alban-Metcalfe, 2004).

Undertaking the Delphi study will further develop my experience and knowledge of undertaking research. Previous experience has been limited to Masters level study and the conduct of several audit projects. Quantitative, exploratory research methodology was used in my Masters project and designing and conducting the Delphi study will further contribute to my research skills and knowledge of research methodologies. Furthermore generating new knowledge in this way will be valuable to the future development of haemato-oncology nursing practice and may also have wider implications for cancer nursing, patient outcomes and the multi-professional team.

Conclusion

This chapter has briefly outlined how the two parts of the project are related and contribute to advancing knowledge for haemato-oncology nursing practice. It is recognised that practising nurses require relevant and up-to-date evidence based knowledge to provide effective care. A textbook assimilating, synthesising, interpreting and disseminating existing knowledge making it more accessible, relevant and therefore useful to practising nurses in haemato-oncology is perceived to be a valuable contribution to advancing knowledge for practice.

Making existing knowledge more accessible and useful to practising nurses is, however, only a part of advancing knowledge for practice. New knowledge acquired through research is also needed to improve the quality of care and keep pace with changes in treatment and healthcare policy. The identification of research priorities is an important first step in developing new knowledge and advancing the knowledge base for practice. This combination of dissemination of existing knowledge and development of new knowledge is perceived to be important to the future development of haemato-oncology practice.

The concept of knowledge was obviously integral to achieving the aim of contributing to expanding and advancing the knowledge base for practising nurses. An exploration of the concept of knowledge therefore forms the basis of the subsequent chapter. Additionally, the potential for my own personal and professional knowledge development through the experience of leading both parts of the project has been identified in this chapter. Reflection and critique of the learning involved in undertaking this project therefore forms another important aspect of subsequent chapters.

CHAPTER 2: KNOWLEDGE FOR HAEMATO-ONCOLOGY NURSING PRACTICE

Introduction

The overall focus of the project 'advancing knowledge for haemato-oncology nursing practice' involved the interpretation, synthesis and organisation of existing knowledge thereby making knowledge more accessible for practising nurses. In achieving this it was, however, important to explore the concept of nursing knowledge; the relevant literature is reviewed in this chapter.

The pace of change in haemato-oncology nursing is, however, rapid. Nurses require to continually develop their knowledge to keep pace with new treatments and the care individuals receiving these treatments and their families require. Yet, the lack of a robust evidence base impedes such development. Identification of evidence deficits and research priorities is therefore required to generate new knowledge to support practice and the following aims and objectives were identified for the project.

Aims

1. Contribute to expanding and advancing the knowledge base for nurses working in the speciality of haemato-oncology
2. Identify research priorities for haemato-oncology nursing
3. Edit and have published second edition of the textbook 'Nursing in Haematological Oncology'

Objectives

1. Undertake a Delphi study to determine research priorities identified by nurses working in haemato-oncology
2. Disseminate results by publication and conference presentation
3. Collaborate with others in writing chapters for the book
4. Review and edit all chapters, ensuring accuracy and consistency of style
5. Provide constructive feedback to authors
6. Prepare the final manuscript for the publishers

Advancing Knowledge for Practice

Definitions of Knowledge

Knowledge is a nebulous concept and has been the subject of extensive debate and discussion. The philosophical study of knowledge is termed epistemology and attempts to answer questions relating to the history, origins and nature of knowledge and how it is derived and validated (Meleis, 1991; Geanellos, 1997). Knowledge is generally defined as awareness or familiarity with facts or experiences (New Collins Concise English Dictionary, 1988). Expanding on this general definition, knowledge is viewed as the integrated culmination of what is known and understood through learning and experience (Johnson & Webber, 2005). Experience and understanding of facts in the practice context is perceived as particularly important in a profession (Perry & Jolley, 1991). Certainly, in the process of developing a textbook for a nursing speciality, assimilating what is known, and making it more accessible and useful for readers, it is vital that facts are related to recognisable practice experience and set within the context of care.

Walker & Avant (1995) define knowledge as the product of knowing. In contrast, Chinn & Kramer (2004) differentiate between 'knowing' as ways of perceiving the world and 'knowledge', a form of knowing that can be shared or communicated with others. The definition of knowing as perception has, however, been challenged as it is argued that perception is indicative of belief (which may or may not be accurate) rather than knowledge which relates to something known to be true (Edwards, 2001). Edwards continues by suggesting that for a belief to represent knowledge there must be some justification or evidence supporting that belief and defines knowledge as "justified true belief" (p26). This view is based on the positivist epistemological paradigm which interprets knowledge as objective truth (McKenna, 1997; Cronin & Rawlings-Anderson, 2004). Evidence of truth is gained from quantitative, scientific research and truth is viewed as irrefutable and unchangeable. Taking this argument to its logical conclusion there can be no such thing as knowledge, only different degrees of belief, as all knowledge is subject to change in the light of new evidence. Knowledge used in skilful nursing practice derived from qualitative research methods or acquired through practice would not, therefore, be recognised from a positivist stance. There are also aspects of practice for which no robust scientific evidence currently exists.

Adler, (undated a, b & c) proposes an alternative philosophical view of truth, knowledge and evidence. He argues that as knowledge may change or be refuted in the future, it cannot be called true. It is therefore more appropriate to claim that, at a given time, specific knowledge is truer than competing alternatives. Knowledge can be distinguished from opinion or belief if it is supported by the strength of rational argument or reasoning (Adler, undated a, b & c). Adler uses the term commonsense knowledge which individuals have about matters of fact and real existence for which there is a definite justification rather than mere opinion. Truth is therefore a probable truth as new and better evidence or reasons may emerge in the future. This view of truth and knowledge is much more congruent with nursing where robust scientific research evidence may not exist to justify actions.

Adler's view is also congruent with both the interpretive epistemological paradigm emphasising truth as knowing derived from people's experiences and the neomodernist perspective of nursing knowledge development that claims to uphold the values of nursing reality by linking science, philosophy and practice (Heidegger, 1962; Reed, 1995; Husserl, 2001). It is argued that scientific knowledge is not viewed as sufficient for the humanity expressed in the intense personal interactions experienced in nursing and use of such knowledge is mediated by its practical value (Simmons, 1992). Reed (1995) supports this view suggesting that there is an epistemological shift from concern over the truth of findings to concern over their practical relevance. Furthermore, Ramprogus (2002) contends that nursing is not a search for truth but a search to achieve 'a certain good' with the main justification for developing nursing knowledge being to produce knowledge for the improvement of patient care. This latter view supports the underlying rationale for developing the textbook.

From a neomodernist perspective nursing embraces a broadened definition of scholarship that employs various key sources for developing nursing knowledge derived from the empirical, conceptual and practice activities of nurses (Reed, 1995).

Knowledge is regarded as both a process and a product and as an open system rather than a fixed set of propositions with truth flowing in a top down fashion. Knowledge requires to be useful in practice and creates truth by being useful. Furthermore, the recognition that people are too complex and individualistic to be treated as objective facts has increasingly led to practice being regarded as a legitimate place to generate and test ideas for developing nursing knowledge (Benner, 1984; Bradley, 1996; Heath, 1998; Higgs et al, 2001). A critical approach is still, however, required through discussion, debate and argument to examine assumptions, reduce bias and enhance credibility and validity (Reed, 1995).

This perspective of knowledge is certainly much more pragmatic and appropriate to nursing practice. Yet, it could be argued that such a philosophy has been developed to provide some credibility to nursing knowledge. The arguments for knowledge derived from practice and qualitative research methods are, however, well established and validated by eminent philosophers and scholars (Heidegger, 1962; Polanyi, 1962; Schon, 1983; Ryle, 1990; Husserl, 2001).

The preceding discussion has highlighted differences in opinion regarding what constitutes knowledge and, while it appears a rather elusive concept, it is apparent that knowledge is acquired in different ways and different types of knowledge exist. It is suggested that in a practice discipline such as nursing, knowledge is viewed collectively as a reasonably accurate account of the world known by members of the discipline and includes different types of knowledge (Chinn & Kramer, 2004). The different types of knowledge important to nursing therefore require to be explored before a body of knowledge for haemato-oncology nursing can be assimilated.

Types of Knowledge

Practical and Theoretical Knowledge

The dichotomy between theoretical and practical knowledge is one of the most widely accepted distinctions between different types of knowledge (Jasimuddin et al, 2005). These distinctions draw on the work of philosophers such as Ryle (1990) and Polanyi (1962) who differentiate between 'knowing that' (theoretical knowledge) and 'knowing how' (knowledge required to perform a skill). Knowing how is further distinguished as there are many activities individuals can perform skilfully without being able to articulate the underpinning theoretical knowledge; for example riding a bicycle (Polanyi, 1962). Knowing how is often referred to as 'tacit' or hidden knowledge (Polanyi, 1962) or 'practical know-how' (Hampton, 1994).

Benner (1984) has been influential in legitimising the concepts of 'knowing how' in nursing. Much knowledge is acquired through practice and is not always articulated and communicated. Knowing how is embedded in practice and expressed through actions, movements, sights and sounds rather than words (Benner, 1984; Chinn & Kramer, 2004). The notion of 'technical rationality' highlights the difficulties in applying theoretical knowledge directly to practice by comparing the messy, confusing problems in the swampy lowlands of practice to the hard high ground of theory (Schon, 1983). It is in the swampy lowlands where the most important and challenging problems of human concern are found. Knowledge developed from actual practice situations is required to develop expertise and find solutions to such problems (Schon, 1983; Benner, 1984). In haemato-oncology nursing, individuals constantly face the life-threatening risks of infection and haemorrhage and their experiences are frequently complex, unpredictable and idiosyncratic and not always amenable to the direct application of theoretical knowledge. Knowledge gained from practice is therefore of immense importance.

Benner (1984) believes that it is the knowledge embedded in clinical expertise that is central to the advancement of nursing knowledge. Theory is refined through practice and reflection on practice with preconceived perceptions and ideas being transformed through encounters with real situations. This expert practice knowledge cannot, however, be gained from a textbook. A textbook can only provide the essential theoretical knowledge that haemato-oncology nurses require as a foundation for making sound clinical judgements, developing expertise and advancing their knowledge. Other types of knowledge therefore require to be explored.

Patterns of Knowing

Most discussions of nursing knowledge are based on the work of Carper (1978) whose seminal paper based on an analysis of the existing literature identified four fundamental patterns of knowing: empirical, ethical, aesthetic and personal as most valuable to nursing. These four patterns of knowing complement each other, are interrelated and equally important (Carper, 1978; Chinn & Kramer, 2004). Carper emphasises that each pattern of knowing is necessary for achieving mastery and no one pattern alone is sufficient. Understanding of the four fundamental patterns of knowing helps increase awareness of the complexity and diversity of nursing knowledge and highlights particular perspectives and their significance (Carper, 1978).

Empirical Knowing

Empirical knowing (the science of nursing) is factual, objective, scientific knowledge that is descriptive and generalisable (Carper, 1978). It can be systematically organised into general laws and abstract theoretical explanations. Empirical knowledge is typically developed scientifically through testing of hypotheses to describe, predict and explain phenomena. It is derived from research and development of theoretical models and acquired from education, textbooks and peer reviewed journals. Empirical knowing is expressed in practice through competent actions based on scientific knowledge and involves conscious problem solving and logical reasoning (Chinn & Kramer, 2004). It has been perceived as the dominant form of knowledge to the detriment of other forms (Carper, 1978; Manley, 1997; Fawcett et al, 2001).

Carper's empirical knowing is based on empiricism, the philosophy of science which believes that knowledge gathered through the senses can be scientifically tested and emphasises quantitative research methods (Manley, 1997, McKenna, 1997). It has been argued that the empirical pattern of knowing needs to be modified to encompass other methods of knowledge development such as phenomenology and grounded theory (White, 1995; Chinn & Kramer, 2004). These methodologies do not fit with the traditional view of empirical knowledge as they seek to enrich understanding rather than produce generalisable facts (White, 1995). Since Carper (1978) first introduced the four patterns of knowing these methodologies have, however, become well established and accepted ways of generating knowledge. Carper also recognised that the four patterns of knowing were dynamic and evolving. For Carper's (1978) model to be useful for practising nurses in the 21st century and in ensuring that this pattern of knowing continues to evolve it would appear both pragmatic and essential to include knowledge derived from all research methodologies within the empirical pattern of knowing.

Aesthetic Knowing

Aesthetic knowing is expressive and relates to the art of nursing. Carper (1978) acknowledges that art is expressive while an aesthetic experience involves creation and/or appreciation. Aesthetic knowledge is expressed through actions, attitudes and interactions rather than words (Chinn & Kramer, 2004). It is subjective and, specific and unique to the situation and the individual. Aesthetic knowing involves perception, intuition, an appreciation of the meaning of a situation and creativity. It is gained by subjective acquaintance and the direct feeling of the experience (Carper, 1978). Carper suggests that patient needs are expressed in their behaviour and aesthetic knowledge involves the nurse's ability to perceive what is significant in that behaviour, at that particular moment, in the context of the whole situation and act creatively to meet the expressed need. Aesthetic knowledge makes it possible to know what to do, and how to be, immediately and without conscious deliberation (Chinn & Kramer, 2004). The nurse's perception of meaning is reflected in the action taken. Experience of previous similar situations and reflection on these experiences are vital components of aesthetic knowledge development. It is also suggested that aesthetic knowledge is developed by envisioning possibilities and rehearsing acts (Chinn & Kramer, 2004).

Personal Knowing

Personal knowing is concerned with discovery of and understanding of self and knowledge of your own beliefs and values. Personal knowledge is a subjective, abstract, inner experience that requires openness to feelings and experiences, honesty with self, being open, genuine and authentic with others, and making genuine efforts to acknowledge and respond to the responses of others (Fawcett et al, 2001; Clarke, 2002; Hood & Leddy, 2006). Knowing the self creates the potential for knowing others better. In the therapeutic use of self, the nurse strives to actualise an authentic personal relationship and engages with the individual. Personal knowing promotes meaning, wholeness and integrity in shared personal relationships and involves reciprocity, a state of being that cannot be described or experienced but only actualised (Carper, 1978). These components of personal knowledge are clearly reflected in the key elements of therapeutic nursing (intimacy, reciprocity and partnership) (Ersser, 1988; Muetzel, 1988; McMahon, 1998).

Personal knowledge is regarded as the most difficult to master and teach (Carper, 1978). It requires an individual to be receptive and reject preconceived notions. Deep reflection on experience through personal narratives and synthesis of perceptions can help to develop personal knowledge (Moch, 1990; Chinn & Kramer, 2004). Teaching and learning strategies, such as opening and centering, can help to increase awareness and understanding of self but multiple methods are required (Clarke, 2002; Chinn & Kramer, 2004). The concept of personal knowledge has been challenged as knowing oneself has been noted to be problematic as our real motivations are unknown to us (Edwards, 2001). Yet, this criticism seems to ignore the statement that 'one does not know about self but strives simply to know self' (Carper, 1978, p18).

Personal knowledge is perceived to be integral to all patterns of knowing (Smith, 1992; Jacobs, 1998). Smith (1992) argues that as meaning is created through the interaction between the individual, what is already known and new knowledge, all knowledge is personal. Certainly, there can be no doubt that the content, extent and context of everyone's personal knowledge is unique. Yet, Smith's argument ignores the interpersonal aspects outlined in Carper's model and interaction is viewed as a vital component of nursing (Meleis, 1991).

Ethical Knowing

Ethical knowledge is formed by knowledge of ethics and morals, matters of obligation and what ought to be done (Carper, 1978). It is concerned with respect for people as individuals, preserving dignity and protecting vulnerability. An understanding of different philosophical positions regarding what is good or right and different ethical frameworks to help guide and direct moral decision making is required. Ethical knowledge does not prescribe a particular course of action but provides insight into possible alternative modes of action to arrive at decisions to protect the best interests of the patient (Clarke, 2002). Ethical knowledge is developed through reflection on practice, and clarifying and valuing issues of rights and responsibilities in practice. It requires sensitivity to the specific circumstances rather than a rule bound approach (Chinn & Kramer, 2004). It is suggested that reflecting on our own ethical decisions helps to clarify our own values. In turn, this can help individuals to understand the decisions of others. Furthermore, ethical knowing (what ought to be done) has been identified as central to caring (Schaefer, 2002).

Carper's four fundamental patterns of knowing recognise that nursing requires more than scientific knowledge and provide a recognised framework for structuring knowledge. Each aspect of this framework is considered to be essential for effective clinical reasoning (Higgs & Titchen, 2000). The model is not, however, without limitations.

Limitations of Carper's model

It is argued that Carper's model has been largely accepted uncritically (Silva et al, 1995; Wainwright, 2000; Titchen & Ersser, 2001). The last authors criticise Carper for not providing details of the methodology and processes used to determine the four patterns of knowing. The paucity of empirical evidence available at that time to help determine non-propositional knowledge is also noted. These comments are very valid. Carper's four types of knowing can, however, be easily identified in most categorisations of knowledge developed since her work was first published adding credibility to her work.

A further criticism of Carper's model proposes that with the exception of empirical knowledge, the ways of knowing cannot be tested empirically and would be more accurately labelled beliefs rather than knowledge (Edwards, 2001; Paley, 2006). These critics are viewing the model from a positivist perspective and fail to recognise the value of other research methods. Edwards (2001) does, however, conclude that perhaps the best way to view Carper's patterns of knowing is as four inter-related areas of knowledge that are relevant to nursing. This is certainly a pragmatic and useful way of considering the model.

Aesthetic knowing is perhaps the most widely criticised aspect of Carper's model. Several authors disagree with Carper's definition of the art of nursing being synonymous with aesthetic knowing (Boykin et al, 1994; Edwards, 1998; de Raeve, 1998; Wainwright 2000; Titchen & Ersser, 2001). The various arguments tend to focus on the lack of distinction between an art and a craft and/or the interpretation of art as a product (artwork or fine art) and the process of creating that product. It is also suggested that art implies creativity and beauty (Rose & Parker, 1994). This latter connotation appears to be at the heart of the distinction between art and aesthetics as aesthetics tends to be interpreted as the philosophy of art related to perception/beauty and involves appreciation. Reed (1995) contends the aesthetic of nursing is found in the beauty and meaning associated with the patient's experiences of health and healing. Carper (1978) however, includes both production and appreciation in her definition of aesthetics. This lack of differentiation between art and aesthetics is not, perhaps, surprising as it appears that both the nature of art and the art of nursing remain ill-defined (Johnson, 1994; Edwards, 1998; LeVasseur, 1999).

It has also been suggested that when the term 'the art of nursing' was first coined it was used metaphorically to capture the indescribable and undefinable aspects of nursing that could not be accounted for by science (LeVasseur, 1999; Austgard, 2006). The interpretation of aesthetic can also be questioned as the word aesthetic originates from the Greek term 'aesthesis' meaning perception, impressions, senses (Austgard, 2006). This latter definition, rather than the artistic context that forms the basis of many of the criticisms of aesthetic knowing, would appear to be far more congruent with Carper's interpretation of aesthetic knowing. This view is supported by the focus on the perceptive, intuitive elements of aesthetic knowing in recent development of Carper's model (Chinn & Kramer, 2004).

Despite the criticisms of Carper's definition and difficulties in defining the art of nursing, most authors agree that the art of nursing exists (Appleton, 1993; Johnson, 1994; De Raeve, 1998; Austgard, 2006). De Raeve (1998) concludes there is some overlap between art and aesthetics and Wainwright (2000) ventures that while nursing is not fine art, it is worthy of aesthetic appreciation. It would therefore appear that while there is some controversy regarding the terminology associated with aesthetic knowing, there is no disagreement that such a pattern of knowing should exist.

It is almost 30 years since Carper's model was published and despite the criticisms levelled at her work, it remains a widely accepted view of nursing knowledge. The model highlights that knowledge encompasses more than science and provides a means of categorising different types of nursing knowledge. The four patterns of knowing contribute to advancing nursing knowledge by helping nurses to understand that knowledge development is complex, diverse and continual (Silva et al, 1995). Furthermore, the development of higher levels of aesthetic and personal knowledge is vital in providing creative and individualised care for patients (Benner et al, 1996). Carper's model is endorsed by Fawcett et al (2001) who claim that the four patterns of knowing encompass most, if not all of the knowledge needed for nursing practice. Carper (1978) did not, however, intend the four fundamental patterns of knowing to be exhaustive and further patterns of knowing have since been suggested.

Unknowing

Munhall (1993) proposes 'unknowing' as a further pattern of knowing. Unknowing involves recognition that a nurse cannot know a patient when they first meet and an openness and alertness to the patients' perception of the situation. Unknowing involves authentically acknowledging that you do not know another person and cannot base your knowledge on empirical, aesthetic, ethical or personal knowledge. Preconceptions about how a patient may be feeling or what is best for them must be rejected to be open to the subjective world of another. Unknowing is a reciprocal process motivated on the part of the nurse, by a genuine desire to find out about and know the patient's world (Munhall, 1993). It is perceived as essential to knowing as without a genuine attempt to discover the patient's perceptions misunderstandings are likely to occur.

Munhall (1993) presents a cogent argument for unknowing as a fifth pattern of knowing. Yet, Heath (1998) suggests that unknowing is related to all patterns of knowing. There will certainly be aspects of unknowing in all dimensions of an individual's knowledge and unknowing is also closely related to personal and aesthetic knowledge. Furthermore, an awareness of unknowing is necessary for all aspects of continuing knowledge development. It would therefore appear to be more useful to accept unknowing as integral to all patterns of knowing rather than create a further pattern of knowing.

Socio-political Knowing

White (1995) suggests that what is missing from Carper's model is the context of care and proposed socio-political knowing as a fifth pattern of knowing. Socio-political knowledge extends the focus from the nurse-patient relationship to the broader context in which nursing and health care take place. It includes social, political and economic factors that affect health and influence nursing roles and health care. Only by possessing knowledge about practice, the profession and health policies will nurses be able to contribute to discussions and influence health care and policy decisions (White, 1995).

White (1995) also emphasises the need to engage with people when they are well and find the commonalities between the health related interests of the public and nursing. This view is congruent with the emphasis on patient focus and public involvement within UK health services (Department of Health (DH), 1999; Scottish Executive

Health Department (SEHD), 2003a, 2004) and illustrates the importance of socio-political knowing.

White (1995) contends that in an economically driven world it would be foolish to ignore the political context and not explore alternative ways of constructing health and health care. Certainly, all aspects of health services are affected by the socio-political context in which they occur. In recent years, the UK government has invested heavily in improving cancer treatment, care and equity of service provision (DH, 2007a). Treatment and care for haematological cancers are expensive (National Institute for Clinical Excellence (NICE), 2003). Resources are, however, finite and service reconfiguration and redesign initiatives are being implemented to improve both outcomes for patients and effectiveness of resource use (DH, 2000a; 2007a; SEHD, 2001a; 2004). Scarcity of nursing expertise is also acknowledged as a problem and affects both the quality of patient care and the health of nurses (Robinson & Dodsworth, 2001; Bosanquet & Sikora, 2004; Ball et al, 2006). White (1995) argues that this fifth pattern of knowing is essential in understanding all the others and it would certainly appear to be remiss to ignore these issues in a project that aims to advance knowledge for haemato-oncology nursing practice.

It has been argued that Carper's (1978) framework encompasses most of the knowledge needed for nursing practice. Socio-political knowledge is, however, also crucial to 21st century nursing practice. These five patterns of knowing have therefore been used as a framework for analysing and reflecting on the textbook and its contribution to advancing knowledge for haemato-oncology nursing practice. It is, however, acknowledged that while a textbook may contribute to aesthetic, ethical and personal knowing and raise awareness of socio-political issues it is predominantly a source of empirical knowledge.

Reflection on the Textbook as a Source of Knowledge

Textbooks can be a valuable source of knowledge and a means of disseminating what is known about a subject. The function of a textbook is "to compile in a single volume the 'state of the art' and the latest research evidence; to create a source of reference for knowledge, offering a kind of 'truth' in relation to what is known about, and what might constitute best practice in a given area" (Corner & Bailey, 2001, pix). The second edition of 'Nursing in Haematological Oncology' intended to continue the process of advancing knowledge for practice commenced in the first edition by assimilating the most recent and relevant evidence, identifying gaps in the evidence base and identifying research priorities to produce a 'state of the art' text.

Empirical Knowing

In achieving the vision of a 'state of the art' textbook for haemato-oncology nurses empirical knowledge contributed significantly. Empirical knowledge is important for haemato-oncology nurses in understanding disease processes, advances in treatments and genetics, the mode of action and effects of treatment, symptom management and the effectiveness of nursing interventions (Grundy 2006b). The traditional interpretation of empirical knowledge does not, however, include or explain the human experience or the complexities associated with nursing practice. Yet, it is imperative that haemato-oncology nurses have knowledge of, and understand patients' experiences gained from qualitative research methodologies. It would therefore be remiss to omit knowledge generated from these studies within a textbook that claims to disseminate what is known.

Despite the potential for a textbook to assimilate, synthesise and present relevant knowledge in a form that is both accessible and understandable to practitioners a major criticism of textbooks as a source of knowledge is their failure to discuss the evidence base and provide references (McKibbon & Marks, 1998; King et al, 2005). In advancing knowledge for haemato-oncology nursing practice it was therefore imperative to ensure that all material included in the textbook was evidence-based.

Yet, review of the reference lists for each chapter of the textbook revealed that the empirical evidence supporting each chapter was largely derived from medicine, HSCT research, textbooks and the general oncology literature. Scientific, empirical knowledge of normal and abnormal haemopoiesis, the pathophysiology of different haematological cancers and clinical trials of different treatments contributed significantly to the first two sections of the textbook.

Little research evidence specific to haemato-oncology nursing was cited reflecting the general paucity of research underpinning this nursing speciality. Much of the empirical evidence underpinning haemato-oncology nursing is therefore derived from general oncology. This evidence is applicable as the principles of haemato-oncology and general oncology nursing are the same. Yet, important differences also exist in haemato-oncology including the aggressive nature of treatments and the resulting increase in severity of side-effects, particularly life-threatening ones such as infection and haemorrhage. Patients also experience more frequent and longer hospital visits/admissions and nurses often form strong relationships with patients and their families (Jackson, 2006). Chapter authors did, however, succeed in using relevant research to support patient care and the information provided could be said to be 'state of the art'. Discussion of existing research was included in all chapters and best practice emphasised. It is recognised that knowledge dissemination is closely related to knowledge creation as dissemination facilitates discussion and further theorising or research thus creating further knowledge (Eraut, 1985). The need for a greater volume of nursing research to underpin the speciality and advance knowledge for practice was, however, highlighted.

The lack of robust research specific to HSCT nursing and psycho-social issues in haemato-oncology has been previously identified (Bakitas Whedon & Wujcik, 1997; McGrath, 2000). Editing the first edition of the textbook also emphasised the paucity of haemato-oncology nursing research and the associated lack of a robust empirical knowledge base. The need to address this issue stimulated the initiation of the Delphi study to identify research priorities and this study is discussed in detail in subsequent chapters. Through the identification of areas for further research new knowledge is created thereby advancing knowledge for haemato-oncology nursing practice.

Aesthetic and Personal Knowing

The expressive and personal nature of aesthetic knowledge makes it difficult to articulate in, and source from the theoretical perspective of a textbook. Aesthetic knowing is a vital component of haemato-oncology nursing where an individual's condition can change rapidly and nurses need to be able to act immediately. Having the ability to empathise and connect with the individual and their families, develop therapeutic relationships and understand the patient's world are all crucial aspects of knowledge.

Similarly, it is difficult for a textbook to be a source of personal knowing. The interpersonal aspects of personal knowledge are of vital importance in haemato-oncology nursing where an understanding of self is required to cope with personal feelings and reactions to cancer and facilitate effective working with patients and families through the disclosed self (Jacobs 1998).

Benner (1984) contends that dialogue around clinical narratives, exchanges and writing of paradigm cases are means of developing expert practice. Incorporating such examples into a textbook may contribute to the development of aesthetic knowledge. Furthermore, encouraging reflection and discussion with colleagues in relation to the experiences of both self and others can be used to help individuals think about issues differently and consider how they use knowledge (Oermann, 2002). These techniques may also facilitate the exploration of experiences and meaning, enhance the knowledge derived from experience and encourage its further development (Eraut, 1985). Aesthetic and personal knowledge development may thereby be facilitated.

Relevance and strong links with readers' personal experience and knowledge also increase learning from text (McNamara & Kintsch, 1996; McNamara et al, 1996: McNamara, 2001). Relevance is thought to stimulate the generation of ideas and connections that readers would not otherwise be able to make. Relevant examples are recognised as indispensable as readers can frequently identify similar personal experiences, demonstrate how content applies to practice and how research findings might be used (Beishuizen et al, 2003; Oermann, 2002: Oermann et al, 2006). Throughout the textbook reflection points, case studies and discussion questions were used to increase relevance and facilitate engagement with the text as ways of encouraging learning and active use of knowledge, thus contributing to the value of a textbook as a means of advancing knowledge for practice. Discussion questions at the end of each chapter were intended to encourage readers to consider how research findings and issues presented in the text may be applied and used in their own practice. Case studies provided a variety of real life examples that aimed to increase understanding and help readers identify with the issues presented.

Readers are however, likely to relate to the information contained in the textbook differently because of their own personal experiences. Discussion of patient perspectives and experiences is perceived to facilitate development of aesthetic and personal patterns of knowing (Benner, 1984). The case studies used to depict patient experiences were, however, written from the perspective of the chapter authors and cannot therefore fully represent patients' experiences and feelings. Replacing these case studies with ones written by patients and families would certainly have increased the patient focus and helped to integrate aesthetic and personal knowing with the other patterns of knowing. This would certainly be a high priority in any future editions.

Ethical Knowing

Ethical knowledge is perceived as essential to haemato-oncology nurses. Ethical knowing was obviously addressed in the ethical issues chapter but was also incorporated into most chapters either explicitly or implicitly. Incorporating ethical issues into many chapters was perceived to be a strength of the text highlighting ethical knowing as integral to all aspects of practice. Robinson & Dodsworth (2001) suggest that the principles of care must be considered before ethical decisions can be made. The principles of cancer care include treating the disease, prolonging quantity and maintaining/improving quality of life, and relief of symptoms and suffering. Ethical dilemmas frequently arise when these principles conflict, particularly if discord exists between nurses' own personal ethical values and their professional concerns to act in the best interests of patients (Robinson & Dodsworth, 2001).

The nature of haemato-oncology raises many ethical and moral concerns in everyday practice and individuals often face difficult decisions. Particular issues include consent to, or refusal of treatment, selection for transplant, issues related to sibling donors and the transition from curative to palliative care. Real life examples of ethical problems were included in the text as a means of increasing the relevance of ethical theories and principles. Through these examples readers are encouraged to reflect on problems they may encounter in their own practice and consider different options in light of individual situations thereby increasing their knowledge, enhancing decision making and integrating ethical knowing with other ways of knowing. Ethical knowing is closely connected to socio-political knowing particularly in relation to the equity of access to health care and the use of scarce resources.

Socio-political Knowing

Historically, nurses have been reticent in becoming engaged in, and influencing, policy and decisions on healthcare (Fatchett, 2001; Boswell et al, 2005). Heavy workloads and feelings of powerlessness have also impeded political involvement and nurses are often excluded from the policy decision making process (Hakesley-Brown & Malone, 2007). A textbook is an ideal medium for raising awareness of the importance and impact of socio-political issues and may encourage readers to have greater involvement in decision making and influencing processes. Nurses working in haemato-oncology need to be aware of socio-political issues and their future implications if they are to pro-actively improve patient care and influence decision making processes.

Socio-political influences on the treatment and care of haematological cancers is integral to several chapters. In responding to political imperatives to increase efficiency and effectiveness national guidelines for improving outcomes for patients with haematological cancer suggest the minimum number of transplants to be carried out annually to maintain expertise (NICE, 2003). Transplant units therefore tend to be centralised and geographically dispersed resulting in psychological, social and financial implications for patients and their families. Discussion of these issues in the fertility, blood and marrow transplantation, children and adolescent chapters should help raise readers' awareness of the impact of policy issues on the context of care and the role of haemato-oncology nurses in decision making and influencing.

Other resource issues relating to survivorship, use of scarce research resources and issues relating to the cost and equity of treatment are included in the ethical issues, psychological issues, immune modulator and novel therapies, research priorities and future issues chapters. Inclusion of these issues should further help raise readers' awareness of the impact of policy issues on the context of care.

The current shortages in registered nurses and difficulties in recruitment and retention combined with demographic changes also mean that nurses need to explore different ways of providing care (RCN, 2007). An entire chapter is devoted to staff support and retention and providing examples of how recruitment and retention can be addressed pro-actively in the current political climate. Different models of providing care are also explored in the blood and marrow transplantation chapter and in detail in the future issues chapter. This content again raises awareness of the impact of demographic and political drivers on future healthcare, the need to consider how care could be provided differently and the need for nurses to be pro-active in influencing decision making that impacts on patient care.

Socio-political knowing is vital to increasing awareness of these issues and helping nurses to analyse the implications of policy for their patients and the service they provide. Leadership is recognised as essential for nurses engaged in influencing and decision making in the NHS (NHS Modernisation Agency, 2002). The leadership chapter emphasises the need to become politically aware and provides suggestions for, and encourages networking.

It is acknowledged that raising awareness of socio-political issues within a textbook will not develop leaders or involve nurses in political influencing but raising awareness is the first step to becoming involved and changing attitudes (Rogers, 1983). The textbook raises awareness of these issues in the particular context in which haemato-oncology nurses work thereby making issues more relevant and pertinent to their own experience. Awareness raising may also provide the stimulus required to explore the socio-political context of care further. One aspect of socio-political knowledge that has not been explicitly addressed in the textbook is, however, patient and public involvement. More explicit attention to this aspect of knowledge would perhaps have enhanced the text.

Disseminating Knowledge

The five patterns of knowing have provided a useful framework for reflecting on the information disseminated within the textbook and emphasised the importance of the different patterns of knowing in advancing knowledge for haemato-oncology nursing practice. Disseminating information in a textbook does, however, suggest that knowledge is simply passed on to others unchanged. Yet, theoretical knowledge is constantly being refined and reprocessed through use (Eraut, 1985, 2000). When theoretical knowledge is used learning takes place and knowledge is transformed, becoming different to before use and being incorporated into the personal knowledge of the individual (Eraut, 1994). Knowledge occurs through interaction with previous knowledge through use of cognitive processes (Kolb, 1984). It cannot just be transmitted through the pages of a textbook. Purkis & Bjornsdottir (2006) contend that the knowledge an individual nurse brings to a patient situation is transformed by that particular situation allowing knowledge to be used creatively in everyday work. The latter authors suggest that it is the intelligent use of knowledge within a particular context that makes an efficient professional.

Furthermore, active use of knowledge increases comprehension (Best et al, 2005). This emphasis on active use of knowledge raises questions regarding how a textbook can advance knowledge for practice and the value of disseminating passive theoretical knowledge in textbooks. If textbooks cannot fully articulate the knowledge required for practice, they must always be incomplete. It is, however, acknowledged that written sources of information cannot adequately represent reality and only form part of the totality of knowledge required for practice (Lamond et al, 1996).

Yet, all professional action makes considerable use of theoretical knowledge combined with knowledge of the patient (Eraut, 1994). Possession of knowledge is also acknowledged as the first step in deciding to implement evidence into practice (Rogers, 1983). The second step is persuasion where a favourable or unfavourable attitude towards something is formed. The challenge for a textbook that aims to disseminate knowledge to advance practice must therefore be to provide information in a way that stimulates different ways of thinking and using knowledge in practice. Reflecting on the textbook using the five patterns of knowing has illustrated how the textbook has addressed this challenge.

Conclusion

This chapter has explored the nature of knowledge and the different types of knowledge that are important and relevant to nursing practice. Different perspectives and opinions regarding the nature of knowledge have been identified and discussed contributing to my understanding of the concept. The traditional empiricist view of knowledge has been criticised for excluding the interpersonal aspects of nursing and it is acknowledged that nurses require more than scientific knowledge. Furthermore, there appears to be increasing recognition and support for an epistemological shift towards the practical relevance of findings and production of knowledge to support the improvement of patient care. This philosophical stance supports the underlying rationale for development of the textbook to be useful to practising nurses.

The four fundamental patterns of knowing (empirical, aesthetic, ethical and personal) (Carper, 1978) and socio-political knowing (White, 1995) were perceived to encompass the different types of knowledge required for nursing practice. Use of this amalgamated framework to analyse and reflect on the textbook facilitated insight into how development of the different types of knowledge can be facilitated within a textbook. It is acknowledged that any textbook can only form part of the knowledge required for practice and that the knowledge base is largely empirical. Analysis and reflection revealed that the empirical evidence supporting the textbook was largely derived from medicine, HSCT research and the general oncology literature emphasising the paucity of research evidence specific to the speciality and highlighting the need to identify research priorities to advance knowledge for practice.

Development of other types of knowledge have also been encouraged and facilitated within the textbook. The use of reflection points, discussion questions and case studies throughout the textbook encourage readers to actively engage with the text and consider the relevance of issues in relation to their own practice experiences. Presenting information in different ways may stimulate different ways of thinking and challenge practitioners to consider how existing knowledge is used in practice thereby contributing to the further development of aesthetic, ethical and personal knowledge. Knowledge of the socio-political context of care is vital for nurses to be able to analyse the implications of policy for their patients and themselves. Although the textbook can only raise awareness of these issues, being increasingly aware of an issue encourages further exploration and contributes to expanding and advancing knowledge for practice.

This chapter has highlighted the importance of the different types of knowledge in expanding and advancing knowledge for haemato-oncology nursing and ways in which the textbook has attempted to encourage and facilitate readers to develop and expand their knowledge. A variety of other factors also affect the value and usefulness of a textbook as a source of knowledge and these factors are critiqued in the subsequent chapter.

CHAPTER 3: CRITICAL REFLECTION ON THE TEXTBOOK

Introduction

Knowledge is valued in practice for improving patient care (Polk, 1989). Many years of working in, and teaching haemato-oncology have provided me with insight into the difficulties many nurses experience in understanding the blood and its diseases. This is congruent with the contention that science texts are difficult to understand (Best et al, 2005). The vision was therefore to collate relevant information in a textbook that would increase understanding and support nurses in advancing their knowledge and providing the care required to address the multiple and complex problems patients may encounter.

Developing an edited textbook that assimilates, synthesises, organises and disseminates relevant knowledge requires careful planning to ensure identification of relevant knowledge, the most appropriate chapter authors and considerable skill on the part of the editor to ensure an organised and cohesive text. Multiple factors can, however, affect the value and usefulness of textbooks as a source of knowledge. This chapter critiques the textbook in relation to these factors and reflects on the editorial process.

Content

Choice of content is vital in determining the usefulness of a textbook as a source of knowledge and in assimilating and synthesising available evidence. Content is largely determined by the objectives of a textbook, target audience and the knowledge of the editor but may also be influenced by independent reviewers engaged by the publishers. Deciding what information should be included and omitted is, however, a skill particularly with an edited book where the editor has to integrate all chapters into a unified book (Nolan & Augustine, 1997).

A second edition of a textbook provides the opportunity for really getting to know the book and update it while retaining its original character (Burnard, 2004). The latter author contends that a second edition usually introduces 25% new material. Slightly more new material was introduced into this textbook with eight new chapters representing a 35% increase. It was originally intended to include two of these chapters 'Adolescents with cancer' and 'Immune Modulators and Novel Therapies' in the first edition but they had to be omitted due to non-completion and difficulties in finding replacement authors. Five new chapters (Sexuality and Nursing Practice, Fatigue, Addressing the Needs of Families, Palliative Care and Research Priorities) were identified following personal reflection on the first edition and awareness of increased professional interest in these issues. The remaining new chapter ‘Leadership Issues’ was identified in conjunction with an independent reviewer. It was anticipated that inclusion of these chapters would enhance the value and usefulness of the textbook for readers.

‘Nursing in Haematological Oncology’ aimed to provide a comprehensive textbook for nurses working with patients with haematological cancers and focused on the knowledge required by practising nurses to provide safe and effective care. No other texts focus on this particular speciality making comparisons difficult when reflecting on content. The appropriateness of content was therefore determined through mapping to a range of HSCT, cancer nursing and medical haematology texts that all contained different degrees of relevant content (Appendix 1).

Section 1: The Diseases

Content of the haematopoiesis chapter was similar to corresponding chapters in other texts although as expected both medical texts were more detailed (Bakitas Whedon & Wujcik, 1997; Hoffbrand et al, 2001; Hughes-Jones et al, 2003). The chapter in ‘Nursing in Haematological Oncology’ was, however, written in greater depth and complexity than the chapter in the other nursing text. Prior knowledge of haematopoiesis is presumed as terms such as erythropoiesis and thrombopoiesis are mentioned in the first pages and the three main blood cell lineages not mentioned until well into the chapter. Other terms such as differentiation and maturation would also have benefited from explanation at an earlier stage. This chapter therefore requires readers to have a relatively high level of prior knowledge and it may be too complex for some readers. In retrospect and considering the target audience for the textbook, defining key terminology earlier in the chapter and simplifying the style may have enhanced the chapter and helped readers to review their knowledge and understanding of normal haematopoiesis. Including a glossary of terms may also have strengthened the text.

'Nursing in Haematological Oncology' included all the haematological cancers included in the medical texts. In general the medical texts were, however, more detailed in relation to pathophysiology, genetics, cytogenetics, histological classifications, diagnostic tests and laboratory findings. This information was intentionally less detailed or purposely omitted from the haemato-oncology nursing text as the depth and level of prior knowledge required for understanding is normally beyond the level expected in pre-registration nursing courses. Inclusion of the detailed prior knowledge required was beyond the scope of this textbook. Comparison of chapters to those in the medical textbooks revealed one additional topic; the structure and function of lymphoid tissue (Hughes-Jones et al, 2003) that might usefully have been incorporated into the nursing text. Yet, overall content encompassed all major issues.

None of the nursing texts reviewed contained chapters related to specific diseases. Yet, Bakitas Whedon & Wujcik (1997) focus on a specific treatment modality and detailed information about the different diseases would not be expected to be included. Furthermore, as there are over 200 different cancers (Corner, 2001) it would have been impossible to include all of these in a reasonably sized and priced cancer nursing textbook. The cancer nursing texts do, however, refer to different cancers in appropriate chapters for example lung cancer is discussed in the breathlessness chapter. The epidemiology, biology and genetics of cancer were also included in both cancer nursing texts supporting the contention that nurses require such knowledge. Nurses cannot understand patients' feelings, experiences and needs if they are unaware of pathophysiology and the effects of treatment. It is perceived that the provision of safe and effective care requires knowledge of both normal and abnormal haematopoiesis and treatment of disease. In advancing knowledge for haemato-oncology nursing practice it was therefore vital to include these issues.

Specific Groups

The textbook would have been incomplete without inclusion of chapters focused on children and adolescents as haematological cancers are the commonest cancers in these age groups (CRUK, 2005; Information and Statistics Division, 2005). Both Corner & Bailey (2001) and Provan (2003) also include specific content on the elderly. Inclusion of content related to the elderly would have been an appropriate addition to 'Nursing in Haematological Oncology' as many blood cancers occur more commonly in the elderly and their needs are frequently different to those of younger patients (Quinn et al, 2001).

Section 2: Treatment

The content of this section corresponds to that included in the nursing and medical texts reviewed and therefore appears appropriate. Yet, in retrospect, much of the content focuses on the technical aspects of treatment and inclusion of more qualitative content focusing on patient experiences and meaning would have enhanced these chapters. This has perhaps resulted in a more technically focused rather than a patient centred text. The dearth of research evidence related to patient experiences (McGrath, 2000) is also likely to have contributed to the technical focus. Greater emphasis on patient and carer perspectives may have enhanced the book as a source of aesthetic knowing.

Section 3: Nursing Issues

Both similarities and differences were apparent in the content of the haemato-oncology nursing text and the other nursing texts reviewed. As would be expected, content in the former text had a much narrower spectrum than the general cancer nursing texts but a broader focus than the HSCT nursing text (Bakitas Whedon & Wujcik, 1997). The haemato-oncology nursing text included most of the main topics covered in this text although the depth of content relating to HSCT was by necessity less detailed. Most of the content of the two cancer nursing texts also appears to have been included in 'Nursing in Haematological Oncology' although not always in the same breadth and depth. Topics included in the cancer nursing texts but not in the haemato-oncology nursing text reflect the broader context of cancer nursing. 'Nursing in Haematological Oncology' does, however, include greater emphasis on issues of specific concern in haemato-oncology nursing including prevention of infection, bleeding problems, oral mucositis, nutrition and family issues.

In retrospect, two topics breathlessness and confusion included in the cancer nursing texts may also have enhanced the haemato-oncology nursing text. Breathlessness, frequently a symptom of anaemia in haematological cancers, is effectively controlled with red blood cell transfusion (Murphy & Pamphilon, 2001). Breathlessness may, however, become increasingly problematic and distressing for patients with chronic disease or disease progression when the need for transfusion increases in frequency (Hughes-Jones et al, 2003). Studies of the nursing management of breathlessness have been conducted mainly with patients with chronic obstructive airways disease and lung cancer (Gift et al, 1992; Corner et al, 1995, 1996; Bredin et al, 1999). No evidence currently exists to support the use of non-pharmacological approaches to breathlessness in haematological cancers specifically. Yet, there is nothing to suggest that these approaches could not be successfully employed. This subject could perhaps have been explored in the palliative care chapter helping to transfer the evidence base from one aspect of cancer nursing to another and helping nurses to consider and use knowledge differently.

Confusion is also associated with advanced haematological cancers where hypercalcaemia and cancer cell infiltration of the central nervous system may occur (Boyle, 2006). Confusion was not, however, discussed in the textbook and inclusion in the palliative care chapter would have been beneficial.

Expanding on the topics of pain, death and bereavement may also have enhanced the text. Pain may be a significant problem for individuals with haematological cancers at the end of life particularly those with myeloma. Pain is discussed as a specific symptom in the myeloma chapter but it may also be problematic in other disorders at the end of life and further discussion of this difficult to manage symptom would have been beneficial in the palliative care chapter. Pain is also significant following HSCT and is included as a separate chapter in Buchsel & Bakitas Whedon (1995). Pain is mentioned in the blood and marrow transplantation chapter but a separate chapter may have enhanced the textbook.

Death and bereavement including spirituality are not discussed in any depth in the palliative care chapter or addressed in any detail elsewhere although a brief section on spirituality is included in the psychological issues chapter. This perpetuates the paucity of spirituality content found in nursing textbooks (McEwan, 2004). The first edition of the textbook included a chapter entitled death, bereavement and spiritual issues and it was anticipated that the palliative care chapter would replace this chapter. In hindsight it would have been appropriate to retain the former chapter as well as including the new palliative care chapter and this will be a further consideration for future editions of the textbook.

Organisation of the Text

The three sections of the book are perceived to be complementary. The first two sections focus on disease and treatment issues that could be viewed as medically orientated (Sohn, 1991). Yet, these sections provide essential underpinning knowledge for effective patient care. Furthermore, many similarities exist between symptoms of the different blood cancers and the side-effects of treatment and they are frequently difficult to separate. To prevent repetition, and increase overall flow and cohesiveness of the textbook, only very specific symptoms and side-effects were discussed within chapters in sections 1 and 2 with common issues being expanded on in section 3 which was the largest section of the text and devoted to nursing issues.

Organisational structure of the text conforms with information processing and learning theories based on the well established principle of working from the known to the unknown which is considered the most important single factor in educational psychology (Quinn, 1995). The extent to which a text overlaps with prior knowledge is also suggested as a major determinant in learning from texts (Kintsch, 1994). Learning from text is restricted by the reader's information processing capacity and the way that text is organised can impede or improve learning (McCrudden et al, 2004). The overall organising structure is therefore perceived as logical and appropriate. It is, however, recognised that working from the known to the unknown is difficult to achieve in a textbook as the knowledge of individual readers is unknown. It was, however, anticipated that the organisational structure starting with normal haematopoiesis, progressing to the diseases, their treatment and nursing issues would support moving from the known to the unknown. Organisational structure is also closely related to comprehension of text.

Comprehension of Text

Most learning from text is based on successful understanding (Kendeou & van den Broek, 2005). Professional textbooks are usually written by experts with extensive knowledge of a particular subject which may appear obvious to them. This may lead to unrealistic assumptions of the amount of prior knowledge possessed by readers and textbooks therefore often lack sufficient background information for less expert readers to understand (Best et al, 2005).

Kintsch (1994) suggests that there are no practical ways of establishing whether individuals will have enough prior knowledge to be able to learn from a textbook. An author or editor can therefore only work from general principles and judgements require to be made. Chapter authors of this textbook were recognised experts and overestimation of the prior knowledge of readers may have occurred. The editing process included reviewing each chapter and determining if the average reader would have sufficient prior knowledge to understand the text. Personal knowledge of haematological cancers, experience of, and familiarity with the content of nurse education programmes over the past 20 years and knowledge of questions frequently asked by both students and less knowledgeable colleagues provided a good baseline for judging the level of previous knowledge. My extensive knowledge of the speciality could, however, also have resulted in overestimation of the previous knowledge of readers. This issue has been previously highlighted in reflecting on the content of the haematopoiesis chapter.

As the book was intended primarily for qualified nurses who had previously studied haematopoiesis and the blood cancers in their pre-registration education, some prior knowledge of key terms was presumed. For many readers their initial education may, however, have been some time ago and recollections of learning may have faded. In attempting to work from the known to the unknown each chapter starts with fundamental knowledge before moving to the more indepth knowledge required by nurses working in a specialist field. It is recognised that the level may be too high for some readers or too low for others. Each chapter was, however, also fully referenced and further reading was suggested at the end of each chapter to provide additional resources for those for whom the text proved too challenging or too limited.

A review of this second edition and reviews of the first edition suggest that the textbook is pitched at the right level for the majority of readers. Yet, book reviews tend to be written by experts and their views do not always concur with those of readers (Pierie et al, 1996). Without formal evaluation it is therefore difficult to reach any firm conclusions on the appropriateness of the level of the textbook.

Clarity of Writing and Cohesion of Text

Clarity of writing and the cohesion of text also impact on comprehension (Dubay, 2004; Best et al, 2005; Kendeou & van den Broek, 2005; Saver, 2006a). Cohesion refers to the way that text is structurally linked and the degree to which readers need to make inferences based on their previous knowledge to make sense of the information presented (Lehman & Schraw, 2002; Best et al, 2005). High cohesion exists when text is explicitly linked to subsequent and preceding text and positively affects information processing and comprehension of key ideas (Lehman & Schraw, 2002).

Ensuring clarity and cohesion are therefore vital components of the editorial role requiring the use of constructive feedback and diplomacy. High cohesion increases recognition and recall of facts (Vidal-Abarca et al, 2000). For those with low levels of previous knowledge it has also been shown to increase deeper levels of understanding (McNamara & Kintsch, 1996). Yet, for those with high levels of previous knowledge deep understanding improves with low cohesion (McNamara et al, 1996; McNamara & Kintsch, 1996). One proposed explanation for this is that low cohesion texts stimulate the use of cognitive processes resulting in activation and integration of prior knowledge with the information contained in text.

Clear written communication is essential in achieving cohesion and results from presenting ideas clearly and logically, choosing the right words, and constructing sentences and paragraphs with care (Goldbort, 2001; Saver, 2006a). This includes ensuring that transitions between sentences, paragraphs and sections are smooth, and language and illustrations are clear (Alley, 2000). Clarity and simplicity are closely linked and require use of language that is precise, clear, forthright, familiar and concise (Alley, 2000; Goldbort, 2001). These attributes are essential for understanding (Alley, 2000).

The ability to write clearly is not, however, a skill everyone possesses and careful selection of authors is vital in producing a clearly written textbook (Nolan & Augustine, 1997; Jacob & Cherry, 2000). Ideally, those with a proven track record in writing for publication would have been chosen as chapter authors. Yet, haemato-oncology is a small speciality and the choice of individuals with both clinical expertise and writing experience is limited. My experience of editing the first edition of the textbook highlighted the writing difficulties experienced by some authors and influenced selection of contributors. It was not, however, always possible to choose contributors with proven writing skills. Chapter authors therefore had varying levels of writing skill with some having written and published extensively and others having no previous experience. Different levels of editorial support were therefore required by different contributors to facilitate clear communication of ideas.

Editors have a crucial role in strengthening authors' writing as much as possible (Alley, 2000). The amount of work and time required should not, however, be underestimated (Burnard, 2004). I erroneously perceived that editing a second edition would be easier than the first edition. Being aware of some of the potential difficulties helped smooth the process but did not substantially reduce the amount of work involved. It was, however, reassuring to realise that other far more prestigious and experienced editors have had similar experiences (Burnard, 2004).

Mateo & Meeker (1992) suggest that supporting novice writers is time consuming and may increase the time required to produce a chapter. It is, however, an investment as it increases the pool of potential authors and contributors to books and journals and is therefore a responsibility of nurse leaders. In my experience although new writers often required more support they were usually enthusiastic, open to advice, tended to have more time than established writers and worked hard to complete chapter drafts on time. The extra editorial time and effort were therefore well worth the investment.

Much of the editing process involved issues of clarity and cohesion. Use of medical terminology also increased the complexity of the text. Several authors contend that articles published in scientific and medical journals are becoming more difficult to read because of the increasingly complex scientific vocabulary (Hayes, 1992; Weeks & Wallace, 2002; Knight, 2003; Hall, 2006; Ludbrook, 2007). Use of medical terminology could not, however, be avoided in a professional textbook. Tips for increasing clarity include avoiding use of jargon, long or ambiguous words, too many acronyms and overly long sentences as meaning may be lost by the time the reader reaches the end (Oermann, 2002; Dubay, 2004; Saver, 2006a). Abbreviations were used within the text as a means of increasing conciseness but were explained and written in full the first time they appeared in the text to increase clarity. Goldbort (2001) maintains that the truest test of readability is for the writer to act as a reader. Putting yourself in the readers' position improves the chances that text will be understood the first time it is read. Searching for gaps in logic, incomplete explanations and anticipating readers' questions can help to increase readability (Saver, 2006a).

I used previous experience of editing, teaching and learning to anticipate questions and ensure explanations included how and why different subjects were related to increase the clarity of text. Each chapter draft was read and reviewed. If a sentence had to be re-read to be understood or was ambiguous it was presumed that readers would have difficulty with understanding and changes to sentence construction were suggested to increase clarity. Being sensitive to the time and effort that an author has put into their writing is, however, important (Nolan & Augustine, 1997; Alley, 2000). It was therefore emphasised that changes were suggestions and that the author could reject changes they were unhappy with, provided this did not detract from the accuracy of the text when the final decision belonged to the editor (Burnard, 2004).

Conciseness

Conciseness is important in textbook development because of specified word limits. Omitting non-essential information and extraneous words contributes to conciseness (Saver, 2006a). Much time was therefore spent scrutinising sentence construction and omitting extraneous words. Decisions about what to include were informed by the established word limit for each chapter and my perceptions of what constituted essential information and best practice as opposed to what might be nice to know. In presenting research findings to practitioners in an understandable way, it is suggested that caution should be exercised in the amount of information provided (Oermann et al, 2006). Presenting essential information, rather than everything that is known or not known about a topic, may help improve readers' awareness of research and change their thinking about their practice (Oermann et al, 2006). Presenting essential information requires analysis and synthesis of evidence and this formed part of the editorial role. Changes to chapters were suggested based on my personal knowledge of both the subject matter and clear writing.

Conciseness can also be increased through the use of diagrams, tables and bulleted lists which help make information more visually accessible and highlight important points (Dubay, 2004; Saver, 2006a; Oermann et al, 2006). These text features were used extensively throughout the textbook. Diagrams enhance understanding and learning by reducing the load on working memory and making relationships explicit more succinctly than text (Carlson et al, 2003). Diagrams may, however, also be misinterpreted (Lowe, 1996; Schönborn et al, 2002). Experts producing diagrams for textbooks have a deeper level of knowledge than readers and diagrams need to have enough visual support to facilitate conceptualisaton of relationships and development of mental models (Lowe, 1996). As the editor I scrutinised diagrams in individual chapters of the textbook for clarity but as I also had substantial knowledge of the speciality, clarity may have been overestimated.

Currency of Evidence

For a textbook to be useful to practitioners it needs to be as up-to-date as possible. The process of developing and publishing a textbook is, however, lengthy and can detract from the currency of evidence. Evidence is often two years old at the time of publication (McKibbon & Marks, 1998; Flemming & Fenton 2002). This may be a particular problem for second editions comprising a mixture of updated and new chapters where completion of chapters at different times may be detrimental to currency. Setting deadlines for submission of chapter drafts is well recognised as a means of overcoming this (Mateo & Kirchhoff, 1992; Nolan & Augustine, 1997; Jacob & Cherry, 2000). Contributors do not, however, always adhere to deadlines, detracting from the currency of evidence submitted on time by other contributors.

In developing this text, some authors updating their chapters completed revised drafts early, within agreed deadlines and some chapters were written two years before publication. Others, writing new chapters or updating chapters written by other authors or chapters that required greater revision took longer to complete. Yet, despite agreements on timescales I had little control over contributors' adherence to timescales and delays were experienced in submission. Some contributors had genuine reasons, such as major life events for non-submission within agreed timescales and revised deadlines were easily negotiated. Others, despite frequent contact and numerous reasons for the delay, failed to submit anything. This situation is common in a multi-author text (Nolan & Augustine, 1997; Jacob & Cherry, 2000; Burnard, 2004). Writing a book chapter may appear to be a good idea when first proposed but may become a burden six months later when the chapter has to be produced and promised chapters may fail to materialise (Burnard, 2004).

Reflecting on these issues, much contact with chapter authors occurred at the beginning of the book development process when format, content, word limits and submission deadlines were being agreed and 6 months into the process after submission or non-submission of the first draft. I initiated less contact in the first six months before the first draft submission date. Closer contact with chapter authors during this time may have led to earlier identification of problem areas and earlier resolution of these issues.

Previous editing experience had highlighted the need to contact authors quickly if chapter drafts were not submitted by agreed deadlines. This usually resulted in a commitment to completing by the due date or within the next few weeks. Contributors appeared reluctant to admit to experiencing difficulties either with finding time or in the writing process. This may be due to underestimation of the time required for writing or perhaps not wanting to admit to experiencing difficulties. On occasions, I suspected difficulties but did not address these until chapter drafts failed to materialise. Acting on these suspicions earlier and entering into a more indepth discussion with the contributor may have reduced some of the delays experienced in receiving chapter drafts and would be a strategy adopted pro-actively in future projects.

Non-return of phone calls and emails was recognised as a sign of non-completion of chapters alerting me to the need to act quickly and be persistent in either finding a solution or another author. Replacement authors had to be found for five chapters due to loss of contact with the original authors or failure to submit chapter manuscripts. Some of the replacement authors produced well written chapters within very short timescales. Finding and approaching the right individuals to write these chapters was, however, time consuming and delayed completion of the textbook by a few months. These delays may have detracted from the currency of the textbook.

The lengthy publication process for textbooks is one reason why journal articles are frequently perceived as more up-to-date. Yet, publication in some of the more prestigious professional journals can also take 1 to 2 years (Baldwin et al, 2002; Oermann, 2002). Furthermore, one research article does not provide sufficient evidence to initiate changes and advance practice. Robust evidence gathered from multiple studies is required to provide a sound rationale (Burns & Grove, 2003).

Textbooks have a greater capacity to assimilate the body of evidence on a range of topics more readily than journal articles that can only contain a small percentage of the information contained in a textbook (Oermann, 2002). Textbooks that communicate specialised knowledge, explain concepts of particular significance, and provide pointers for practice and improving patient care are also perceived to be valuable to practitioners (Flemming & Fenton, 2002).

Ethical and Legal Issues

Plagiarism

The potential for plagiarism was highlighted in editing the first edition of the textbook when several incidents were identified. Plagiarism relates to the use of another person's work without acknowledgement of the original source of the material and is viewed as intellectual dishonesty (Oermann, 2002). It also includes reproducing your own previously published work without acknowledging the previous citation and this was certainly one of the problems encountered in the first edition. I was therefore acutely aware of the potential for plagiarism and the importance of detecting it. Fortunately, fewer episodes of plagiarism were detected in the second edition and these were overcome relatively easily. It has been suggested that plagiarism is increasing as many authors are unaware of committing plagiarism because they have not learned the rules of professional writing (Nones Cronin, 2003). Authors have frequently been found to be unaware of copyright issues and the need to apply for permission for any diagrams, figures and tables used in their chapters (Saver, 2006b). This is congruent with my personal experience as contributors who did plagiarise appeared to be unaware of their mistake. Ignorance is not, however, a recognised defence (Oermann, 2002). These experiences highlight the responsibility placed on an editor to be knowledgeable about published literature in the speciality, and legal and ethical issues in publishing to protect copyright and detect plagiarism. In editing the textbook, every effort was made to conform with ethical and legal guidelines. It cannot, however, be guaranteed that some unacknowledged material has not inadvertently been included.

Conclusion

The aim of the textbook was to provide a comprehensive source of knowledge for nurses working with individuals with haematological cancers. Production of a state of the art text requires inclusion of the body of knowledge required to provide safe and effective care in a form that is engaging, informative and understandable. This chapter has reflected on the factors that may affect the value and usefulness of the textbook as a means of supporting nurses to increase their understanding and advance their knowledge. The range and appropriateness of content is obviously vital in determining the usefulness and value of a textbook. Analysis and reflection on content provided support for the overall appropriateness of content and the inclusion of essential knowledge. The identification of additional topics that could have been included in the textbook has also provided invaluable information for improving and enhancing the value and usefulness of any future editions.

Reflection on the textbook has also increased my understanding of the importance of organisation, clarity and cohesion of text in relation to readers' comprehension. This knowledge has raised my awareness of the potential for overestimating the average reader's level of previous knowledge and will be indispensable in increasing my effectiveness and the clarity and cohesion of any future editing ventures.

Reflection and critique of the editing process have also emphasised the crucial role of the editor in producing a state of the art text. The amount of time and effort required to produce a textbook or write an individual chapter has been reinforced providing a greater awareness of the need to communicate such information to chapter authors. The importance of choosing authors with the enthusiasm, motivation and time to write has also been reiterated thus increasing my awareness of the importance of communication with, and support of, authors in the early stages of an editing project.

Both this chapter and the preceding chapter have reflected on the types of knowledge and the specific topics that practising nursing need to be knowledgeable about in relation to haematological cancers. Although some aspects have been identified that could have improved or added value to the text it is perceived that the text assimilates, interprets and synthesises, in one volume, available research and the fundamental knowledge required by practising nurses to provide safe and effective care to individuals. The lack of empirical knowledge specific to haemato-oncology nursing already identified does, however, detract from this assertion.

The need to increase the amount of research in the speciality is obviously vital to strengthening and advancing the knowledge base for practice. Research does, however, need to be undertaken in an informed and systematic manner with exploration of existing research being the first step in the process. Research also requires to be relevant to both changes in clinical practice and developments in healthcare policy affecting the context in which care takes place. Policy developments and existing research are therefore examined in the subsequent chapter.

CHAPTER 4: LITERATURE REVIEW: RESEARCH IN HAEMATO-ONCOLOGY NURSING

Introduction

To be of real world value research needs to be focused on and relevant to practice. Research should therefore be influenced by those issues that are important to practising nurses, patients and their families. The context of care may also affect the experiences of patients and healthcare practitioners and the processes, outcomes and quality of treatment and care. Healthcare policy developments therefore also need to be considered in the context of future research. This chapter commences with an overview of relevant healthcare policy developments in the USA, Europe and the UK before searching and reviewing the existing research undertaken in haemato-oncology nursing as a foundation for informing future research.

The Impact of Cancer on Health Services

Cancer remains one of leading causes of morbidity and mortality in the USA and Europe (U.S. Department of Health and Human Services (DHHS); 2007; Boyle et al, 2003a). More people are surviving cancer and incidence rates are predicted to increase due to changing demographics and the trend towards an ageing population while mortality rates are predicted to decrease (DHHS, 2000; Boyle et al, 2003a; Ludwig, 2006: National Cancer Institute (NCI), 2007; Verdeccia et al, 2007; Ferlay et al, 2007). In the foreseeable future an increasing number of people will therefore be living with cancer placing increased demands on already stretched health services to provide treatment and care.

In attempting to reduce the demand for cancer services, strategies emphasising public health approaches and prevention of cancer have been developed in North America, the European Union (EU) and the UK (DHHS, 2000; Decision 1786/2002/EC; DH 2000a; SEHD, 2001a; Department of Health, Social Services and Public Safety, 2006; Department of Health and Children, National Cancer Forum, 2006; Welsh Assembly, 2006). These strategies are also influenced by overarching healthcare policy focused on increasing health care service availability and accessibility. In the future more care will be delivered outside hospital and closer to home. These policy imperatives are concerned with improving the quality, safety, cost and value of treatment and care, recruiting and retaining a competent health care workforce, increasing patient involvement and patient choice and encouraging people to take more responsibility for their own health (DH, 2004, 2005; SEHD, 2004, 2005a; DHHS, 2007).

Policy Developments in Cancer Care

Common themes can be identified in the cancer strategies of different countries including: reducing the incidence of cancer through prevention and early detection, developing improved and more effective treatments, ensuring the best outcomes for all by understanding the factors that influence outcomes, providing consistent and high quality care, improving quality of life for individuals, reducing disparities between different groups by improving equity of access to screening, diagnosis and cancer treatments, investing in staff and service infrastructure, establishing national standards for cancer care and developing comprehensive research strategies aimed at improving treatment and care.

Implementation of such strategies, however, differs within and between countries. In the USA it is estimated that approximately half of all individual states have a cancer control plan (Curry et al, 2003). Developments are, however, currently underway to improve this situation by encouraging partnerships between private organisations and local health departments to develop programmes to prevent cancer and improve quality by disseminating best practice guidelines, monitoring the quality of cancer care and improving access to screening and healthcare particularly for those disadvantaged by lack of health insurance (National Cancer Policy Board, 2000; Curry et al, 2003).

In Europe, the EU has no legislative power over health care in individual nations. Health is high on national political agendas and few countries want EU intervention in domestic health policy (Duncan, 2002). It does, however, encourage strengthening of the Community's overall capacities by further developing cooperation between member states (Decision No 1350/2007/EC). The European Code against Cancer Action Plan initiated in 1987 and the European Public Health Action programme have also encouraged progress in relation to cooperation between European researchers and cancer registries across Europe (Micheli et al, 2003; Smyth, 2008).

Cancer Strategies and Haematological Cancers

It is estimated that as much as 50% of cancers can be prevented by addressing lifestyle issues such as smoking cessation, improving diet, exercise, physical activity and weight control (DHHS, 2000). Furthermore, patient outcomes tend to be much better if cancers are diagnosed at an early stage. While these approaches are to be commended they focus largely on solid tumours. Although a small number of cases of acute myeloid leukaemia are associated with tobacco consumption causes of haematological cancers are generally less easily identified and largely associated with genetics (Boyle et al, 2003a). Preventative lifestyle measures are therefore unlikely to be effective in reducing the incidence of haematological cancers and no effective screening programmes exist.

Furthermore, in contrast to the common cancers survival rates are not always influenced by early diagnosis and treatment particularly for some chronic leukaemias or low grade lymphomas where a watch and wait policy is advocated or where the aim of treatment is disease control rather than cure (Atkinson & Richardson, 2006; Aurora & Winter, 2006).

Other aspects of cancer strategies therefore are more significant for haematological cancers, particularly improving patient outcomes through new diagnostic approaches, effective treatment and participation in clinical trials and research into the genetic and chromosomal abnormalities associated with these diseases. In Europe and the UK, collaboration between haematologists is high and most patients are entered into national clinical trials to ensure the most appropriate treatment (NICE, 2003). The diagnosis and treatment of cancer is complex and the best results are obtained when care and treatment are carried out by multidisciplinary teams who see sufficient numbers of patients to develop expertise (Richards, 2007). The relative rarity of haematological cancers in comparison to solid tumours means that the number of individuals seen in any one centre is also likely to be small. Following implementation of NICE (2003) guidance, haematological cancers in the UK are now managed by multi-disciplinary teams serving relatively large populations of ≥500,000 and services are centralised in specialist centres with the expertise and facilities required. Centres where expertise and facilities are provided can be geographically distant and travel may be difficult for some patients and their relatives. NICE (2003) also recommended that a Clinical Nurse Specialist with specific training in counselling, communication and ethics be included in the multi-disciplinary team to support patients. The extent of education and training undertaken by clinical nurse specialists to meet these recommendations is unknown as is the availability of such education.

Investment in Cancer Services

Reducing the cost of cancer care is a priority in the USA, Europe and the UK. In the UK, investment in cancer services has been increased since the introduction of the various cancer strategies in individual countries. Continued financial increases are, however, unlikely to be sustained indefinitely and ways of improving efficiency and effectiveness are being explored. Currently, individuals with haematological cancers receive expensive chemotherapy treatments and HSCT requires the one to one care required in a high dependency unit (NICE, 2003). Hospital stays also tend to be lengthy. In England financial control for services has changed with primary care trusts commissioning health services (DH, 2002a). Developments such as payment by results already used in the USA and several other European countries to encourage partnerships between private organisations and the health sector are also expected to lead to increases in efficiency, effectiveness and quality of health services (DH, 2002b). Reducing waiting lists and the length of inpatient stays are major costs saving and form part of these initiatives (Feachem et al, 2002; Ham et al, 2003). These financial control initiatives may impact on the way that services for haematological cancers are delivered in the future with a greater focus on ambulatory and outpatient care. Ambulatory care has been introduced in the USA but is rare in the UK (Ritchie, 2005). Financial control measures have not been adopted in other UK countries and the impact on services in England is likely to be closely observed.

Research

The development of new knowledge through cancer research is an important part of improving cancer care (Smyth, 2008). In the USA, Europe and the UK different research organisations exist to improve research infrastructure, coordinate research activity, identify gaps in current research and address previously neglected areas of research with the ultimate aim of increasing survival, improving the effectiveness of treatment and quality of life (National Cancer Research Institute (UK), 2005; National Cancer Institute (US), 2006; Ireland-Northern Ireland- National Cancer Institute Cancer Consortium, 2006; European Organisation for Research and Treatment of Cancer (EORTC), 2007). For HSCT, the European Group for Blood and Marrow Transplantation (EBMT) facilitates and supports collaborative research.

To date these organisations have primarily focused on understanding the causes and biology of cancer, early detection, diagnosis, treatment effectiveness and survival outcomes. Research funding has therefore been largely allocated to scientists and physicians and nursing research has traditionally been poorly funded in comparison. Small numbers of active nurse researchers also contribute to the difficulties in building research infrastructure and capacity (DH, 2000b; SEHD, 2003b). This position is, however, starting to improve. The recommendations of the SEHD (2003b) report have been implemented, research alliances have been established across Scotland and initiatives implemented to build research capacity. Further recommendations have recently been accepted in the UK aimed at increasing nursing research capacity and capability, developing clinical/academic careers and enabling nurses to compete with other health care professionals for funding (UK Clinical Research Collaboration, 2007). These initiatives, are, however, only the start and require to be continued if nursing research capacity and output are to increase substantially.

The important contribution of nursing research to improving patient care has also been recognised through recent legislation in the USA. The "Assuring and Improving Cancer Treatment Education and Cancer Symptom Management Act of 2008" directs the National Institutes of Health to provide research grants for registered nurses as principle investigators and to expand programmes of research improving treatment and management of symptoms and side-effects of cancer and cancer treatment and evaluating the role of nursing interventions in side-effect management (Summary of H.R.5585, 2008). This development is encouraging and may lead the way for increased funding of nursing research in other countries.

Identifying the nursing contribution to safe and effective care and the effect of nursing on patient outcomes is becoming increasingly important in demonstrating clinical effectiveness and improving quality (SEHD, 2001b; 2005b; 2006). In common with nurses in other specialities haemato-oncology nurses need to be able to demonstrate the effectiveness of their interventions. Research is required to demonstrate effectiveness but nursing research initiatives have been criticised for lacking a clear strategy and vision and being fragmented (DH, 1993).

In addressing these issues research priorities need to be identified and a coordinated strategic approach taken to future research. This would appear to be particularly relevant to a small speciality such as haemato-oncology where the small numbers of patients seen in any one centre, suggest that a coordinated multi-centre approach to research is required. However, before research priorities and a strategic approach can be developed, existing research needs to be identified. The following literature review therefore analyses existing haemato-oncology nursing research with a view to informing future research.

Previous Reviews

Three reviews of the HSCT nursing research have previously been undertaken. A review of the BMT literature in the Cumulative Index of Nursing and Allied Health Literature (CINAHL) between 1980-1991 identified 134 articles with 87 obtained by the reviewer (Haberman, 1995). Only 13 appear to be research papers and it is not known how many of the unretrieved articles were research studies. A further review confined to the North American BMT nursing literature between 1982 and 1995 revealed 222 publications (Haberman, 1997). Only 33 were research papers. There is substantial overlap in the time scales between these two reviews and the differences in the number of research studies retrieved suggest that either a number of research papers were included in the 47 papers not retrieved by Haberman, (1995) or research activity had increased towards the end of the second review period.

The third review based on a worldwide search of the BMT literature in CINAHL between 1980 and mid-1996 found 44 research articles (Molassiotis, 1997a). Again substantial overlap exists between this review and Haberman (1997). The small increase in the number of research studies identified by Molassiotis (1997a) reflects the paucity of research activity outside North America.

HSCT is not the treatment of choice for all haematological cancers and the last three reviews do not incorporate research relating to conditions not suitable for HSCT. A further review provides an overview of the available research (from all disciplines) focusing on the emotional, social and spiritual aspects of haematological cancers (McGrath, 2000). Much of the research included in this review also focuses on HSCT and the paucity of research associated with haematological cancers is highlighted. A review of all aspects of haemato-oncology nursing does not yet appear to have been undertaken. It was therefore decided to undertake a search of the nursing literature for the decade between 1996 and March 2006 to establish the volume of research and the topics explored across the entire spectrum of haemato-oncology nursing.

Search Strategy

The search was confined to the CINAHL database as only research undertaken by nurses was being sought. Using the key words of bone marrow transplantation, haemopoietic stem cell transplantation, haematological malignancies/neoplasms/ cancers, haemato-oncology, leukaemia, lymphoma and myeloma, and limiting the search to research and English language, 1061 articles were found.

Studies addressing HSCT for breast cancer or including individuals with haematological cancers as a small proportion of larger heterogeneous populations were excluded. Medical, dental and paediatric research, doctoral dissertations and book abstracts were also excluded. Studies focusing mainly on adults with haematological cancers but including individuals with solid tumours or children as $\leq$50% of the sample were, however, included. A total of 84 studies were identified but as one study was unobtainable from the British Library only 83 were reviewed. Some overlap exists between this search and the search undertaken by Molassiotis (1997a) with six articles published in 1996 appearing in both searches (Brandt et al, 1996; Gaston-Johansson & Foxall, 1996; Greco et al, 1996; Molassiotis & Haberman, 1996; Shuster et al, 1996; Thain & Gibbon, 1996).

Organisation of Retrieved Research

The knowledge domains addressed by the research retrieved, appeared to fit broadly with the six conceptual fields developed by the University of Washington School of Nursing: individual adaptation to wellness and illness, family adaptation to wellness and illness, supporting and non-supporting environments, physiological therapeutics, psychosocial therapeutics and foundations for professional practice (Haberman, 1995). This conceptual framework was therefore used to organise the research (Appendix 2). The term 'interventions' was used to replace 'therapeutics' as it was thought to be more meaningful terminology in the UK context. All studies included in the review are summarised in Appendix 3.

Over half the research articles (44) were included in the individual adaptation to wellness and illness domain and four overarching themes were identified: quality of life (14 studies), patient experiences (11 studies), side-effects of treatment (11 studies) and psychological effects and adaptation (8 studies). Only a few other topics, in any domain, focused on the same topic. For this reason studies included in the four identified themes are reviewed in greater depth followed by an overview of the studies included in the other domains.

1. Individual Adaptation to Wellness and Illness

This domain incorporates the strategies used by individuals to promote health and aid recovery from illness. It encompasses prevention of disease and disability and facilitating rehabilitation (Haberman, 1995). The four themes are inter-related and a degree of overlap exists between them. Quality of life (QoL) is affected by patient experiences, side effects and the psychological impact of disease and treatment.

Conversely, side-effects and psychological issues affect QoL and the experience of individuals and their families.

Including both QoL and side-effects in this domain deviates from the original categorisation where QoL was included in the psychological therapeutics domain (Haberman, 1995). QoL is, however, subjective and as the studies retrieved explored the impact of treatment or side-effects on QoL rather than any intervention it was thought to be more appropriate to include it in this domain.

Haberman (1995) does not mention the impact of the side-effects of treatment on individuals although studies appear to be included in the physiological interventions domain. As studies retrieved for this review did not address interventions it was perceived to be more appropriate to include them in this domain.

Quality of Life

Quality of life was the most commonly researched topic in this review and in the reviews of Haberman (1997 (n=5)) and Molassiotis (1997a (n=10)). A further study including QoL as one of several measures is included in the supporting and non-supporting environments domain. The increase in the number of QoL studies in haemato-oncology nursing reflects the overall increase in QoL studies in the cancer literature generally (King, 2006).

QoL is acknowledged as an important concept in judging the value of cancer treatments (Hjermstad & Kaasa, 1995; Byar et al, 2005). The nature of high dose treatments and subsequent severity of side-effects make QoL particularly important in haemato-oncology. QoL is used as the gold standard for outcome measurement in clinical trials and is important for planning and implementing rehabilitation and psychosocial services (King et al 1997; Molassiotis & Morris, 1999).

QoL has been previously identified as a research priority for haemato-oncology nursing (Molassiotis, 1997a) and oncology nursing (Rustøen & Schjølberg, 2000; Ropka et al, 2002; Berger et al, 2005). The concept has been extensively researched in cancer. Until recently, however, only a few studies exclusively examined QoL for those with haematological cancers (Molassiotis, 2006). Slightly over half of the QoL studies in this review (9) focused on HSCT (Gaston-Johansson & Foxall, 1996; Molassiotis et al, 1996a; Molassiotis & Morris, 1998; 1999; Edman et al, 2001; Larsen et al, 2003; Hacker & Ferrans, 2003; So et al, 2003; Byar et al, 2005). The majority (5) included a variety of haematological cancers (Edman et al, 2001; Hacker & Ferrans, 2003; Larsen et al, 2003; So et al, 2003; Byar et al, 2005). Both Larsen et al (2003) and Byar et al (2005) also included small numbers of individuals with solid tumours in their samples.

The remaining studies included individuals either post-HSCT or receiving other treatments and all explored QoL for specific conditions; lymphoma (Gaston-Johansson & Foxall, 1996; Beser & Öz 2005), chronic myeloid leukaemia (Molassiotis & Morris, 1998; 1999), chronic leukaemia (Bertero et al, 1997a), acute and chronic leukaemia (Bertero et al, 1997b), acute leukaemia and lymphoma (Persson et al, 2001) and myeloma (Poulos et al, 2001). Interest in specific conditions may have increased because of increased long-term survival following HSCT producing larger research populations. Conditions affecting a mainly older age group, or when treatment intent is to control rather than cure the disease are, however, not well represented within QoL studies.

Individuals with aplastic anaemia are not included in any studies and people with chronic leukaemias (other than CML) are only included in two studies (Bertero et al, 1997a & b). Only small numbers of individuals with myeloma are included in studies and the one study focusing specifically on myeloma explores the effect of pain and mood disturbance on QoL rather than overall QoL. Similarly, those with myelodysplastic syndromes are only represented in one study exploring the effect of fatigue on QoL (So et al, 2003). Furthermore, only two studies include individuals who have relapsed (Persson et al, 2001; Edman et al, 2001). Perceptions of QoL for those with a poor prognosis may well be different to those with a good prognosis and no research appears to investigate these issues.

A variety of different factors make it difficult to compare results of studies. Different types of treatments and conditioning regimens were included. Individuals undergoing different types of transplant have been found to have significantly different experiences in physical symptoms, role functioning, leisure activities and sexual functioning (Molassiotis et al, 1996a; Zittoun et al, 1997). A predisposition to small sample sizes also makes it difficult to draw conclusions from the results. Sample sizes ranged from 15 (Bertero et al, 1997a) to 206 (Poulos et al, 2001). Half the studies had sample sizes smaller than 30 and only 2 were greater than 100. Despite the differences between studies and the difficulties associated with interpreting results haematological cancers and their treatment do appear to impact significantly on QoL. The majority of studies acknowledge their limitations and suggest findings warrant further investigation.

Perceptions of QoL may change over time and longitudinal studies help nurses understand the patient experience. Timescales for QoL measurement vary between studies ranging from before chemotherapy commenced (Beser & Öz, 2005) to 5 years post-HSCT (Edman et al, 2001). Several studies suggest a longitudinal approach was used (Gaston-Johannson & Foxall, 1996; Persson et al, 2001; Hacker & Ferrans 2003) but only Persson et al (2001) who studied the concept over 2 years really explored the concept over the disease trajectory. The other 2 studies used relatively short time-frames; 20 days and 6 weeks post-HSCT. Previous QoL research has indicated that most patients achieve a ceiling effect approximately 2 years post-HSCT and there is little further change over time (Andrykowski et al, 1989). This research is now rather dated and techniques and treatment regimens have changed. Further longitudinal research may therefore be valuable.

Long term survivors (mean 40 months post-HSCT) have also demonstrated moderate levels of psycho-social dysfunction (Molassiotis et al, 1996a). Furthermore, three studies have identified difficulties with returning to employment following HSCT (Molassiotis, 1996a; Molassiotis & Morris 1998; 1999). A dearth of research relating to employment following cancer treatment, in a UK context, has been noted in the wider QoL and survivorship literature (Molassiotis, 2006) and appears to be another important area for future research.

Patient Experiences

Few patient experience studies have been included in previous reviews; 3 studies (Haberman, 1997) and 4 studies Molassiotis (1997a) one of which (Thain & Gibbon, 1996) is also included in this review. The majority of studies in this review (n=6) focus on the HSCT experience (Thain & Gibbon, 1996; Shuster et al, 1996; Cooper & Powell, 1998; Cohen & Ley, 2000; Jones & Chapman, 2000; Stephens, 2005). The non-HSCT studies included 2 studies exploring the experience of survivors of leukaemia and lymphoma (Persson et al, 1997; Persson & Hallberg, 2004), 2 studies exploring the experiences of, and decisions to, undertake exercise as an intervention for treatment related fatigue (Coon & Coleman, 2004a & b) and one study exploring interactions between adults with leukaemia and their nurses (Bertero, 1998).

Relatively little is known about patient experiences of haematological cancers although this area of research is becoming increasingly important with the current emphasis on public and patient involvement in care and in designing and evaluating interventions to meet patient needs (SEHD, 2003c; DH, 2005). The current paucity of knowledge related to patient experiences is reflected in the predominance of qualitative approaches, used in all studies except Persson et al, (1997). The latter authors used a quantitative questionnaire based on the results of a small qualitative study (n=5) undertaken prior to the start date of this review (Persson et al, 1995). Apart from the latter study and Bertero (1998) who used participant observation all studies used interviews and subsequent content analysis of data.

Qualitative studies are frequently criticised for their lack of attention to reliability and validity and it is suggested that the decisions made by the researcher should be clearly identified (auditability) (Lincoln & Guba 1985). All studies reviewed provided a clear outline of the processes used to analyse data. However, only Cohen & Ley (2000), and Persson & Hallberg (2004) used more than one researcher to validate data and studies are therefore open to bias. Neither of these researchers attempted to establish the trustworthiness of data by asking patients to validate their interpretations.

The qualitative nature of most patient experience studies means that sample sizes are small ranging from 4 (Bertero, 1998) to 21 (Coon & Coleman, 2004a & b). The potential for sampling bias also exists in these studies. It is possible that those who were more unwell chose not to participate and others may have declined to participate because it was too painful or difficult to relate their experiences. Samples may therefore include individuals who wanted to explore their experience more deeply, or perhaps be more articulate.

In the HSCT studies different transplant procedures were included. Furthermore, in at least two studies (Thain & Gibbon, 1996; Jones & Chapman, 2000) participants underwent the transplant procedure in a different hospital to the one where they had received previous treatments. Established relationships with health care professionals were therefore lost at a time when individuals were feeling at their most vulnerable and this may have affected their perceptions of their experience particularly as interpersonal relationships with nurses have been noted as an important source of support for individuals undergoing HSCT (McGrath, 2000).

The majority of HSCT studies were retrospective. McGrath (2000) contends that all retrospective studies are positively biased as participants have already survived the experience. All retrospective studies employed unstructured interviews with one data collection point although the time frame varied both in and between studies. Time between the actual HSCT procedure and interviews may have affected the results as recall may be less accurate when time has elapsed since the experience (Bowling, 1997). Negative memories may fade or be repressed and relief at having survived may alter perceptions of experiences (McGrath, 2000).

Prospective studies are able to compare experience both before and after a procedure and more accurately assess the changes and consequences that result from it (Polit & Hungler, 1991). Yet, the results of the prospective studies undertaken by Cooper & Powell (1998) and Stephens (2005) have remarkable similarities to the results of the retrospective studies challenging McGrath's contention and supporting the assertion that traumatic memories remain vivid over time (Christianson & Loftus, 1991). Further research is required to substantiate or refute these findings.

Several consistent themes were identified in the different studies: fear of death and recurrence combined with uncertainly about survival and future relapse, a sense of loss both for their previous life and loss of control over their own body, changing self-concept, inability to return to the life they had previously, the wish to leave the protective confines of their isolation room and the insecurities experienced on return home, being unprepared for the physical intensity of pain or their emotional responses and the importance of relationships with the family and nursing staff. This brief summary of findings certainly does not reflect the richness of the data but a consistent theme across all studies is the substantial impact of HSCT on the lives of recipients. It also highlights the need to design and evaluate nursing interventions to prepare individuals for, and support them during and after HSCT.

In a further prospective study the importance of social relations was also a major theme (Shuster et al, 1996). Yet, other results appear different to those of the retrospective studies. Themes identified in this study included: physiological concerns, reduced alertness and wanting to sleep as means of escaping from the reality of the situation, avoiding social contact, spirituality and acknowledging that attitudes towards illness changed their experience. Ignoring issues was one way of denying what was happening and not thinking about things. Participants in this study were relatively young the majority being in their 20s and the oldest being 51 and this may be one reason for the differences in results as age groups in other studies appear to be older.

Individual experiences of becoming ill with acute leukaemia or highly malignant lymphoma also appear to be similar to the main themes identified in retrospective HSCT studies (Persson & Hallberg, 2004). Within the confines of this literature review it is not possible to discuss in detail all the differences between studies. One particularly significant finding in the latter study was, however, related to age. Individuals in the older age group (average age 61) had lost belief in, and were scared of the future. They had struggled through a period of illness and thought it had not been worth the effort and they had paid too high a price for survival. Fear of the future prevented them enjoying life. These findings combined with the findings of Schuster et al (1996) suggest that exploration of the experiences of different age groups could be a useful focus for future research.

Recognising and understanding the patient perspective across the disease trajectory is important and further exploration is obviously required. Few studies explore the experiences of those receiving treatments other than HSCT. The small volume of literature exploring experiences of those with haematological cancers contrasts with the vast amount of literature exploring patients' perspectives of having cancer (Richardson et al, 2001). These authors, however, suggest that cancer nursing research makes few links between patient experiences and testing of nursing interventions to manage specific issues or support patients. Future research focusing on the testing of interventions to improve patient outcomes would also make a valuable contribution to developing the nursing evidence base in haemato-oncology.

Side-Effects of Treatment

A total of 11 studies focused on the side-effects of treatment. Pain and oral mucositis were addressed by three studies each (David & Musgrave 1996; McGuire et al, 1998; Pederson & Parran 1999a & b; (the last two papers reported the quantitative and qualitative approaches used in a single study) Borbasi et al, 2002; Salvador, 2005). Two studies addressed fatigue (Molassiotis 1999a; El-Banna et al, 2004) and the remaining three single studies addressed anorexia and weight loss (Molassiotis, 2003), the frequency and troublesomeness of side-effects associated with a specific chemotherapy regimen (Sitzia et al, 1997) and symptom occurrence, intensity and distress (Larsen et al, 2004). Given the severity of side-effects following treatment and their potential to persist for a considerable period of time and interfere with daily activities the paucity of research addressing side-effects is surprising.

Pain and Mucositis

Individuals with haematological cancer have a higher incidence of mucositis than those with solid tumours and for HSCT recipients it is an inevitable consequence (Madeya, 1996; Rubenstein et al, 2004). Mucositis causes severe pain and is associated with a significant increase in risk of infection, days of fever and parenteral nutrition, use of opioid analgesia and 100 day mortality (Woo et al, 1993; Madeya, 1996; Sonis et al, 2001). Pain and mucositis have not featured strongly in previous reviews. Haberman (1997) identified two studies focusing on mucositis and none were identified by Molassiotis (1997a) (although three studies address interventions for mucositis).

All papers, except Salvador (2005) who examined factors influencing oral mucositis addressed the experience, frequency and severity of pain and/or mucositis. All papers focused on HSCT recipients except McGuire et al (1998) where a minority of individuals (n=4) were receiving high dose chemotherapy for acute leukaemia.

All studies were quantitative and used different measurement instruments. Salvador (2005) undertook a retrospective record review and as variables could not be controlled results are only as good as the records reviewed. McGuire et al, (1998) used several measurement instruments all with well established reliability and validity. Reliability and validity of data collection instruments were not tested by David & Musgrave (1996) and no reference is made to reliability and validity for one of the data collection instruments used by Pederson & Parran (1999b). This lack of discussion makes it difficult to determine the rigour of studies. A further instrument adapted for the latter study was, however, assessed for content validity and internal consistency. For the qualitative studies Pederson & Parran (1999a) checked their interview guide for content validity. Data from both qualitative studies were analysed by more than one researcher.

All samples were convenience or purposive with sample sizes ranging from 6 (Borbasi et al, 2002) to 140 (Salvador, 2005). Furthermore, half the sample died during the former study further reducing sample size (Borbasi et al, 2002). Frequency of data collection varied between studies and several studies had missing data because patients felt too unwell to complete the data collection instruments (McGuire et al, 1998;

Pederson & Parran 1999a & b; Borbasi et al, 2002). These difficulties highlight the problems associated with undertaking prospective research in populations of very sick people and it is possible that the impact of the various side-effects is underreported in these studies.

The differences between studies also make it difficult to compare results. These studies do, however, highlight the effects of pain and mucositis in this patient population. Yet, they do not explore the management of symptoms or the impact of patient education and supported self-care measures on the individual experience and these issues provide a basis for future research.

The importance of regular assessment of the oral cavity, optimum frequency of oral care, choice of oral care agents and tools in the detection and management of mucositis is well documented (Miller & Kearney, 2001; Dickenson & Porter, 2006). The evidence base underpinning these issues is, however, inconclusive. Several, recent, major reviews of the oral mucositis literature have identified a deficiency in robust research underpinning oral care and interventions for oral mucositis (Rubenstein et al, 2004; Sonis et al, 2004; Worthington et al, 2006). The last authors identified the need for well designed and conducted trials with sufficient numbers of participants to perform subgroup analyses by type of disease and chemotherapeutic agent. This would be a massive undertaking and highlights the need for multi-disciplinary and multi-centre research. It does, however, present exciting opportunities for nurses to take the lead in some of this research.

Fatigue

No research on this topic was identified in the three previous HSCT reviews. This is not surprising as it is only in recent years that cancer related fatigue has become recognised. Four other studies addressing different aspects of fatigue are included in other domains in this review. One study exploring the impact of fatigue on QoL has already been discussed (So et al, 2003). Two studies are included in the physiological interventions domain (Coleman et al, 2003; So & Tai, 2005) and a further study in the psychological interventions domain (Kim & Kim, 2005a). The latter three studies demonstrate the increasing interest in interventions to alleviate this side-effect.

Fatigue appears to be a significant problem for individuals with haematological cancers. It is common at diagnosis (Savage et al, 1997; Wang et al, 2002) and individuals with haematological cancers also appear to experience severe fatigue more frequently than those with solid tumours (Cleeland & Wang, 1999). Fatigue is one of the commonest reported side-effects in HSCT survivors and has been found to persist after treatment particularly in older individuals (>60 years) (Andrykowski et al, 1990; Belec, 1992; Bush et al, 1995; Molassiotis et al, 1995a; 1996a; Molassiotis, 1999a; Molassiotis & Morris, 1999; Knobel et al, 2000; Loge et al, 2000; So et al, 2003).

Both fatigue studies included in this domain used quantitative approaches with different measurement instruments and different patient populations. El-Banna et al (2004) prospectively studied lymphoma patients receiving autologous HSCT whereas Molassiotis (1999a) undertook a retrospective study of HSCT survivors and individuals receiving maintenance chemotherapy. Both studies attempted to correlate fatigue with other symptoms. Molassiotis (1999a) explored relationships between tiredness and lack of energy and numerous other variables and El-Banna et al (2004) focused on the relationship between fatigue and depression. Both studies used different, although well validated, data collection instruments and it is clear that fatigue correlates significantly with a number of other variables, including depression, psychosocial adjustment, difficulty concentrating, dizziness, physical symptoms and adjustment with their social environment. Correlation does not, however, indicate cause and effect. Mood disorders such as depression and anxiety may also cause fatigue and symptoms often co-exist and relationships between symptoms and cause and effect mechanisms in fatigue are unclear (De Jong et al, 2002).

The differences between the 2 studies make it difficult to compare results. Furthermore fatigue is known to both persist and change over time (Richardson et al, 1998) and both these studies only provide a snapshot either at one particular time point or over a short time frame. Longitudinal studies would provide more information about patterns of fatigue over time. These studies do not indicate how fatigue is perceived by patients or the impact on daily life and these issues provide a basis for future research.

Remaining Studies Addressing Side-Effects

The single study focusing on anorexia and weight loss was a secondary analysis of previous research (Molassiotis, 2003). Findings therefore require to be substantiated with primary research. Malnutrition is well recognised as it is the most common secondary diagnosis in individuals with cancer and associated with poor quality of life, decreased response to treatment and shortened survival (Nitenberg & Raynaud, 2000; Wilson, 2000). Furthermore, multiple factors indicate that individuals with haematological cancers may be at increased risk of malnutrition particularly HSCT recipients who frequently require parenteral nutrition (Mehmet, 2006). An extensive literature on nutritional issues and cancer exists. The paucity of haemato-oncology nursing research on the subject is therefore somewhat surprising. Except for one study addressing nutritional assessment identified in the reviews of both Haberman (1997) and Molassiotis (1997a) there appears to have been no nursing research on nutritional issues in this patient group.

The remaining two studies addressing side-effects explored the incidence, severity and distress caused by specific symptoms (Sitzia et al, 1997; Larsen et al, 2004). There appears to be scant research addressing distress associated with side-effects with only one study previously identified (McGrath, 2000). Psycho-social distress is, however, also explored in some studies included in the psychological effects section.

The two studies in this review focused on different populations (lymphoma & HSCT) making it difficult to generalise results. A number of side-effects that individuals found distressing were, however, identified that do not appear to have been addressed by haemato-oncology nursing research for example infection, alopecia, nausea and vomiting, taste changes, breathlessness, dry mouth, peripheral neuropathy, sleep disturbances, night sweats, constipation, feeling depressed and anxious, skin changes. Although some of these issues such as alopecia, and nausea and vomiting have been addressed in the cancer nursing research literature, the increased severity of side-effects experienced by individuals with haematological cancers suggests that research specific to this population is warranted. More specific HSCT related side-effects such as graft versus host disease (GvHD) and bleeding problems are also absent from haemato-oncology nursing research and need to be explored to strengthen the evidence base for practice.

A rather disjointed approach to research focusing on side-effects appears to have emerged with no one side-effect receiving particular attention. However, individuals receiving treatment for haematological cancers usually experience multiple side-effects simultaneously and side-effects are often inter-related for example pain and mucositis. The concept of symptom clusters (two or more symptoms that are related to one another and occur together) has recently emerged in the cancer nursing literature (Dodd et al, 2001; Dodd et al, 2004; Beck et al, 2005; Kim et al, 2005). It may therefore be more useful for future research to explore symptom clusters in haemato-oncology rather than focusing on individual side-effects of treatment.

Psychological Effects and Adaptation

Few studies addressed psychological effects and adaptation. The paucity of research exploring psychological experiences and issues has, however, previously been highlighted (McGrath, 2000). The number of studies retrieved from this search (eight) is slightly higher than the five identified by Molassiotis (1997a). Two of the studies in the latter review focused on hope and Haberman (1997) included the same two studies (one of which is a paediatric study). Haberman (1995) identified no studies associated with this theme.

All eight studies included HSCT recipients although one study also included individuals receiving maintenance chemotherapy as a comparative group (Molassiotis et al, 1997). Different types of transplant and conditioning treatments were included in individual studies and 43% of participants in one study (Fife et al, 2000) had solid tumours making it difficult to compare results.

Studies also focused on different issues; hope (Saleh & Brockopp, 2001a), spirituality, (Cohen et al, 2000), decision making (Bywater & Atkins, 2001), adaptation and distress (Molassiotis et al, 1996b; Fife et al, 2000), social/family support (Molassiotis et al, 1997), late psychosocial effects (Molassiotis, 1996), and psychosocial transitions in long term survivors (Molassiotis, 1997b). The paucity of research addressing the psycho-social consequences of survivorship has previously been identified (McGrath, 2000). In this review survivorship issues were also identified in QoL and patient experience studies. The need for interventions to support coping and adaptation appears to be a consistent theme and research exploring the effectiveness of such interventions would appear to be required.

Qualitative approaches were used in three studies (Cohen et al 2000; Bywater & Atkins, 2001; Saleh & Brockopp 2001a). Different research designs were used in all three studies (case study, grounded theory, phenomenology). All other studies used quantitative approaches although Molassiotis (1997b) also treated the results of a factor analysis as qualitative data. The latter study was also the only retrospective study in this theme. Most studies were descriptive/exploratory. One study was a secondary analysis of data that aimed to overcome some of the difficulties associated with research on the same subjects over a long period of time (for example costs and mortality) (Molassiotis, 1997b). Two further studies used longitudinal designs in an attempt to overcome some of the issues related to changes over time (Molassiotis et al, 1996b; Fife et al, 2000). Four studies recruited from several different centres in an attempt to overcome some of the criticisms relating to generalizability (Molassiotis, 1996; Molassiotis, et al, 1996b; Molassiotis et al, 1997; Fife et al, 2000). Sample sizes ranged from 7 –164.

Few previous studies have explored experiences before, as well as during transplant and the effects of these experiences on psychosocial adjustment. In addressing this deficit both Molassiotis et al (1996b) and Fife et al (2000) undertook prospective studies albeit with different time scales and collected data collection before, during and after HSCT.

Both Molassiotis et al (1996b) and Fife et al (2000) used a number of different data collection instruments with well established reliability and validity. Additional data collection instruments were either devised or modified in both studies with attention given to content validity and internal consistency. Similarities exist in the variables measured despite the different measurement instruments used. Both studies measured emotional response/mood state, symptom distress, coping style/strategies, body image/self-image, independence and dependence/support.

Completing a large number of data collection instruments at several time points would have been onerous for participants. Fife et al (2000) acknowledge this and not all measurement instruments were completed at all seven time points. Those variables considered to be most susceptible to rapid change were measured at each time point. The criteria used to make this judgement are unknown. At least three measurement instruments were completed at all time points. Some participants were, however, too unwell to complete the questionnaires at all time points resulting in missing data. It is therefore possible that some psychological effects may have been missed and the degree of psychological distress experienced underestimated.

Despite these limitations, both studies found that emotional distress was highest in the pre-transplant phase and those individuals who were highly distressed at this time were also most distressed throughout hospitalisation and sometimes after discharge. Maintaining control was a significant coping strategy with greater perceived control associated with lower emotional distress (Molassiotis et al, 1996b; Fife et al, 2000). Psychological support was also found to be invaluable in both studies.

Contradictory results were also apparent between the last two studies in relation to the degree of emotional distress at and post-discharge and in correlations between symptom distress and, anxiety and depression. A consistent theme was, however, the need for psychological help and support at crucial phases in the HSCT process. Identification of critical phases and evaluation of effective interventions would appear to be valuable directions for future research.

Sexual concerns and dysfunction emerged as significant causes of distress in two studies (Molassiotis, 1996; Molassiotis, 1997b). Sexual concerns have also been noted to affect QoL (Molassiotis et al, 1995b; Molassiotis & Morris, 1999). Research on sexuality has previously been noted as scanty but indicates that patients may face profound treatment related adjustment problems in relation to sexuality (McGrath, 2000). Research focusing on interventions and support to help individuals address sexual issues would therefore appear to be important.

2. Family Adaptation to Wellness and Illness

This domain focuses on the coping strategies of families faced with a life-threatening illness (Haberman, 1995). A total of seven single studies addressing different topics were included in this domain. Molassiotis, (1997a) also identified seven studies in his review while no studies were identified by Haberman (1995; 1997).

Families play a key role in supporting people with haematological cancers (Kelly, 2006). Most research focuses on the families of children and few studies address the family and other relationships of adult patients (Thain & Gibbon, 1996; McGrath, 2000). Donation of blood or marrow stem cells is a specific consideration for this population and the few studies that explore this issue suggest that donors may experience a substantially increased emotional burden in supporting their sick relative in addition to physical concerns (Morrison et al, 1998; Williams et al, 2003). Furthermore, little evidence exists on the experience of adult sibling donors. The lack of empirical work addressing donor issues has been previously noted (McGrath, 2000). Caregiver issues and the impact of HSCT on family/spouse have also been identified as both a priority and direction for future research in HSCT nursing (Haberman, 1997; Molassiotis, 1997a). Financial hardship caused by illness and the impact on the family is a further area not addressed by research (McGrath, 2000). These issues present important opportunities for future research programmes.

3. Supporting and Non-supporting Environments

A total of six articles referring to both internal and external environments and the physical, psychosocial and cultural properties which may impact on an individual's health and well-being were identified. This represents a slight increase on other reviews with the same two studies being identified by Molassiotis, (1997a) and Haberman, (1997) and no studies by Haberman (1995).

Outpatient transplantation and protective isolation were the main themes identified in this domain. Infection control techniques and protective isolation have previously been identified as research priorities Molassiotis (1997a). Protective isolation has been found to be a psychologically difficult experience for patients although only one study in this review and a small number of previous studies focus on the experience (McGrath, 2000). Isolation techniques and practices are also controversial issues in haemato-oncology nursing as they are difficult topics to research requiring large samples and multi-centre studies to acquire robust results (Hart, 2006).

Outpatient transplantation is being undertaken in the USA but is not yet common in the UK. However, receiving care closer to home reflects current UK government policy (SEHD, 2005a; DH, 2006). Little research relating to organisational/role development or nurse led services in cancer nursing generally in the UK exists (Richardson, et al, 2002). Furthermore, the need to test models of nurse led follow up, continuity of care, home care and role development have been previously identified (Haberman, 1997). Future research is obviously required to build a sound evidence base on which to develop appropriate services for patients.

4. Physiological Interventions

Eight studies focused on the physical interventions used to help individuals and families cope with the impact of illness. The number of studies found in this review appears to be slightly less than the ten identified by Molassiotis (1997a). However, only six of those identified by Molassiotis appear to evaluate the impact of a nursing intervention. One study focused on children and a further study (Brandt et al, 1996) is also included in this review. Remaining studies appear to describe interventions used or describe symptoms rather than evaluating interventions. It is also difficult to determine how many of the papers included in this domain by Haberman (1995; 1997) are actually intervention studies.

Most studies are single studies. Two address interventions for fatigue reflecting the increased interest in this topic (Coleman et al, 2003; So & Tai, 2005). To date, most fatigue intervention studies have focused on breast cancer. In the wider literature a small number of studies do, however, demonstrate the positive effects of exercise on fatigue for individuals with haematological cancers particularly following high dose chemotherapy and HSCT (Dimeo et al, 1997; 1998; 1999; 2003; 2004; Oldervoll et al, 2003). Most studies examining the impact of exercise have used aerobic exercise e.g. walking, stationary bike. Except Dimeo et al (2003) studies have included a relatively young age group (≤60 years). Those with bone metastases have also been excluded from most studies. More evidence of the effectiveness of cardiovascular and resistance training is required for older individuals and those with bony involvement. The pilot study by Coleman et al (2003) starts to address these issues but the work requires to be replicated with a larger sample.

The small number of studies identified in this domain reflects the general cancer nursing research in the UK with few studies investigating the effectiveness of specific nursing interventions (Richardson et al, 2001). Again the need to link nursing care with patient outcomes has been previously identified (Haberman, 1997). Management of several symptoms (nausea and vomiting, pain, graft-versus-host disease, pulmonary oedema) have also been previously identified as research priorities (Molasiotis, 1997a). To date these recommendations and priorities do not seem to have been used to inform research strategies.

5. Psychosocial Interventions

Eight studies addressed psychosocial interventions used to help individuals and families cope with the impact of illness. Haberman (1995) acknowledges that the boundaries between physical and psychological are often blurred and the boundaries between these domains are rather artificial. This is highlighted by the study exploring a psychological intervention for fatigue (Kim & Kim, 2005a) which is closely related to the studies exploring physiological interventions for fatigue. The number of studies included in this domain represents a slight decrease to the 11 studies identified by Molassiotis (1997a). However, Molassiotis included QoL in this domain and nine of the studies identified in his study related to QoL. The remaining two studies explored patient experiences and these studies were included in the individual adaptation domain in this review. The number of studies identified in this review therefore represents a 100% increase since the review conducted by Molassiotis (1997a). Furthermore, no studies evaluating psychological interventions appear to have been identified by Haberman, 1995; 1997). The studies identified in this review therefore appear to represent new areas of research.

6. Professional Foundations for Practice

Ten articles which contribute to nursing as a discipline are included here. Haberman (1995) suggests that development of instruments for teaching or documenting care does not form a formal field of nursing knowledge and separates this literature from the six domains of nursing knowledge. The development of instruments for improving care and research is, however, an important aspect of developing professional nursing practice and for this reason studies exploring the development of such instruments were included within this domain. The number of studies in this domain represents a slight increase to those identified in previous reviews (Haberman (1995; 1997) (3) and Molassiotis (1997a) (9)). Informed consent and nursing stress appear to be common across the reviews (although only identified in single studies). The hope raised by HSCT and lengthy periods of hospitalisation frequently result in the formation of close relationships between nurses, patient and their families. If patients die, nurses can experience loss and grief reactions and the lack of research exploring emotional coping and stress in health care professionals working in haemato-oncology has been previously emphasised (McGrath, 2000).

A number of directions for future research have previously been identified within this domain including; support for nurses, ethical issues, skill mix and staff ratios, recruitment and retention and the development of standardised instruments for clinical assessment for quality of life, pain and fatigue (Haberman, 1997). The findings of the current review appear to support the continuing relevance of these areas for future research.

Comparison to Previous Reviews

This review has both similarities and differences to those of Haberman (1997) and Molassiotis (1997a). Haberman noted that much of the research reviewed comprised small sample sizes, descriptive or correlational designs and cross-sectional or single time point data collection. Whereas, Molassiotis (1997a) commented on the increase in qualitative studies and the retrospective nature of many studies, and suggests that sample sizes had tended to increase over the previous few years. Between 1996 and 2006 the increase in qualitative studies does not appear to have been sustained with a greater number of quantitative studies. Furthermore, in common with much nursing research small sample sizes are still prevalent.

The number of studies identified in this review has almost doubled since the previous review (n=44) (Molassiotis, 1997a). Most studies in the latter review were conducted in North America and this review shows an increase in research in other parts of the world Europe (n=36), North America (n=37), South America (n=1) and Australia and Asia (n=9).

Molassiotis (1997a) confined his search to the HSCT literature whereas this search explored haemato-oncology nursing generally. Most studies 64 (77%) in this review were also related to HSCT. Only 19 studies focused on non-HSCT related issues highlighting the lack of evidence underpinning the full scope of haemato-oncology nursing. The paucity of research in this speciality is particularly apparent if the results of this worldwide search are compared to a 20 year search confined to the UK cancer nursing research literature which identified 227 primary research articles between 1980 and 2000 (Richardson et al, 2001). Lack of a coordinated approach to research in haemato-oncology nursing is apparent from these findings.

The focus on HSCT also means that studies focus mainly on a younger age group. Allogeneic transplants are rarely considered over the age of 55 due to the aggressive nature of the procedure. Autologous transplants may be used in an older population but treatment decisions are based on the individual (Richardson & Atkinson, 2006). Individuals with conditions that tend to occur later in life such as chronic leukaemia, myeloma and lymphomas are therefore underrepresented in the nursing research. Demographic changes predict an increase in the numbers of elderly people and consequently a rise in the number of elderly people with haematological cancers (CRUK, 2006). Research addressing the needs of elderly people would therefore be valuable.

The HSCT research also tends to focus on those who have survived and done well. The dearth of literature exploring palliative and end of life care for haematological cancers has recently been highlighted in the allied health literature (McGrath, 2001a & b; 2002a & b; McGrath & Holewa, 2006; 2007). As many haematological cancers remain incurable, further research in this area would appear to be vital.

Conclusion

The literature review clearly demonstrates the paucity of research in haemato-oncology nursing. Research undertaken in the last decade focuses on a diverse range of topics. The volume of research is, however, low and there are few aspects of care where a body of evidence can be said to exist. Over half the studies reviewed were included in four overarching and inter-related themes, quality of life, patient experiences, side-effects of treatment and psychological effects and adaptation. Contradictory findings, lack of replication, small sample sizes and methodological differences detract from the quality of research. Review of existing research has highlighted the lack of a coordinated approach with individual researchers developing research based on their own particular interests.

Important areas for future research were, however, identified particularly for those with conditions not treated by HSCT, the elderly, those with a poor prognosis and those who are surviving longer. The importance of further research focused on patient and family experience (particularly sibling donors), the need for more prospective studies, the importance of research investigating the effectiveness of nursing interventions and research exploring organisational issues including the context of care, role development and nurse-led care were also highlighted. These areas of research are congruent with current healthcare policy developments and clearly important as topics for future research.

Further research is, however, required to strengthen the evidence base for practice and advance nursing knowledge. While this review has identified some important areas for future research previous criticisms of nursing research such as lack of a clear strategy and fragmentation (DH, 1993) are, however, apparent and no consensus exists regarding the most important issues. Furthermore insufficient information was elicited to allow identification of research priorities. The small number of active researchers, scarcity of research funding and the relatively small number of individuals with haematological cancer seen in any one centre emphasise the importance of developing a coordinated systematic approach to future research. Identification of research priorities is acknowledged as the first step in developing a systematic approach to research and a study aiming to gain consensus on research priorities in haemato-oncology nursing was therefore undertaken. The methodology for this study is discussed in the following chapter.

CHAPTER 5: METHODOLOGY

Introduction

Research is broadly categorised into two main approaches qualitative and quantitative. These approaches have differing philosophical underpinnings and are frequently represented as opposing ends of a continuum (Crossan, 2003). Quantitative research is regarded as a deductive, scientific method building from general principles to theory development and testing of hypotheses. It is concerned with demonstrating cause and effect, measurement and objectivity (Bowling, 1997; Cresswell, 2003). Qualitative research utilises an inductive approach starting with general observations from practice and building up ideas and general statements through data collection. Values, meanings, beliefs, thoughts and feelings are emphasised (Cresswell, 2003; Halcombe & Andrew, 2005).

Nursing research is, however, complex and purely qualitative or quantitative approaches may not capture all the dimensions of the particular phenomena being studied. It is increasingly recognised that not all research methods fit neatly into one or other research approach and mixed methods research is now far more prevalent (Cresswell, 2003; Rolfe, 2004). As little is known about research priorities in haemato-oncology nursing an initial qualitative approach to identifying priorities appeared to be most appropriate. Subsequently a quantitative approach would be needed to determine the perceived importance of each of the identified priority areas. Mixed methodology therefore appeared to be appropriate for this study. Such an approach is congruent with sequential triangulation where the results of one method of data collection are used as the basis for the direction of the other (Morse, 1991).

Aims of the Study

The study aimed to:

1. determine research priorities of UK nurses working in haemato-oncology

2. contribute to expanding and advancing the knowledge base for nurses working in the speciality through dissemination of findings

Choice of Research Methodology

Determining Research Priorities

Several different methods have been used to determine research priorities including surveys, the Delphi approach and face to face methods such as consensus conferences or workshops, focus groups and nominal group technique (Bond & Bond, 1982; Fink et al, 1984, Bowling, 1997; Black et al, 1999; Mead & Moseley, 2001a). All of these methods have their advantages and limitations. The latter 3 methods all bring together small groups of people and the small sample sizes may not be representative of the whole population. The potential for bias therefore exists particularly if the views of group members are known to and concur with those of the researcher (Fink et al, 1984; Lane et al, 2001; Williams & Webb, 1994). Haemato-oncology is a small speciality and units tend to be geographically distant. The difficulties involved in identifying a representative sample, complex logistics and the financial cost required to conduct a series of face-to-face data collecting events in different locations were perceived to be major disadvantages to the use of these techniques for the current study.

Surveys

Surveys are means of collecting data from a large number of geographically dispersed people (Bowling, 1997). Survey methodology has been used for numerous studies seeking to establish research priorities (e.g. Bakker & Fitch, 1998; Rustøen & Schjølberg, 2000; Ropka et al, 2002; Berger et al, 2005). All these studies have constructed a questionnaire for the survey based on the results of previous studies identifying research priorities. As the literature review provided insufficient information from which to construct a questionnaire for research priorities in haemato-oncology nursing, survey methodology was not thought to be appropriate for this study.

Delphi Approach

The Delphi approach has been used extensively for establishing research priorities and appears to be the most frequently used method. It has been extensively used in health services research as a method of obtaining consensus on various issues (McKenna, 1994; Beretta, 1996; Keeney et al, 2001). The Delphi approach combines qualitative and quantitative research methods through the generation of qualitative primary data and subsequent quantitative analysis (Broomfield & Humphris, 2001). The Delphi approach also has the reputation for being most useful for issues that benefit from collective subjective judgements rather than precise analysis (Reid, 1988).

Sequential rounds of structured questionnaires are used to gather information (Wilhelm, 2001). The first round is usually qualitative and aims to elicit a response to a broad question. Subsequent rounds build on responses to the previous one and are returned to participants (Beretta, 1996). Information about group opinion is therefore available to all participants. The approach is viewed as particularly appropriate when little knowledge exists about an issue, in policy making when there is uncertainty about priorities and in research aiming to identify opinions and ideological positions (Jones & Hunter, 2000; Hardy et al, 2004; Mead & Moseley, 2001a). It is also thought to be the most appropriate method for participants who have diverse backgrounds, where more research subjects are required than can meet face to face and when meeting of subjects is not feasible (Bayley et al, 2004). It is also recognised as an inexpensive method of reaching large numbers of geographically dispersed people (Jones & Hunter, 2000). The Delphi approach therefore appeared to be particularly suitable for this study as the potential pool of participants was large and geographically dispersed.

The Delphi approach was specifically designed to retain the positive aspects of face to face groups such as knowledge from a range of sources and creativity while overcoming some of their disadvantages such as opinions being influenced by a dominant individual (Rowe & Wright, 1999). It allows experts who have not previously communicated to do so and provides an arena where all participants are heard equally (Butterworth & Bishop, 1995).

All research methods have their limitations and the Delphi approach is no exception. Large amounts of qualitative data tend to be generated in the first round and can be unwieldy and difficult to manage. Co-ordinating large groups and several rounds can be complicated and time consuming, participants may become fatigued after 2 or 3 rounds and high attrition rates are noted and may affect the validity of results (Fink et al, 1984; Mitchell, 1991; Procter & Hunt, 1994). In common with other research methods, methodological problems exist in relation to establishing the expertise and size of the panel and lack of standardised methodological guidelines (Sackman, 1975; Williams & Webb, 1994; Crisp et al, 1997). Methodological rigour in individual studies is required to overcome these criticisms and reduce the effect of these limitations.

Despite these limitations, the Delphi approach does appear to be the most appropriate research approach for the current study as the initial qualitative round allows exploration of an area where little is known and qualitative and quantitative approaches are combined within the research methodology allowing the initial qualitative data to be used within the same research design. It also appears to be the best means of accessing a representative sample of geographically dispersed people within a limited budget.

Use of the Delphi Approach

The Delphi study originated from the Rand corporation in the early 1950s and aimed to "obtain the most reliable consensus of opinion" from a group of experts (Dalkey & Helmer, 1963, p458). Over time the original Delphi technique has been modified and adapted and several different forms of Delphi study are identified in the literature. The conventional (classic), real-time, policy and decision Delphi appear to be most frequently cited (Turoff, 1970; Linstone & Turoff, 1975; Rauch 1979). These variations demonstrate the many different applications of the Delphi technique across different professions and industries. Irrespective of the type of Delphi study the same format is used consisting of sequential rounds of structured questionnaires to gather information (Wilhelm, 2001).

In undertaking a Delphi study decisions require to be made in the context of the individual study. Decisions need to be made regarding the number of rounds, characteristics of anonymity, involvement of experts, iteration and controlled feedback and consensus that distinguish Delphi from other group responses (Rowe et al, 1991; Woudenberg, 1991). These issues are discussed in relation to the current study.

Number of Rounds

The classic Delphi study suggests 4 rounds (Young & Hogben, 1978) but generally 2 or 3 are used with the number of rounds usually being determined by the amount of time and funding available (Keeney et al, 2001). As limited time was available for this study 2 rounds were initially proposed. The Delphi technique is, however, recognised as an iterative process (McKenna, 1994) and a third round remained a possibility.

Anonymity

Anonymity aims to allow responses to be made freely without the influence of peer pressure (Dalkey & Helmer, 1963). Sackman (1975) criticises this stance claiming that anonymity may result in less thought being given to responses and feelings of lack of responsibility for the final result. Yet, there does not appear to be any evidence to suggest that respondents give any less thought to responses in a Delphi study than they would to any other type of postal questionnaire. This criticism therefore appears to be somewhat unjustified.

It is also acknowledged that complete anonymity in Delphi studies cannot be guaranteed due to the iteration process as the researcher is aware of individual responses (McKenna, 1994). Furthermore, respondents may be known to each other as work colleagues (Keeney et al, 2001). This may be an issue in the current study as some respondents may work in the same place and discuss their responses with one another. Knowing other respondents may, however, also be an advantage as Keeney et al (2006) suggest that knowing other participants has the potential effect of increasing the response rate.

Sampling and Choice of Expert Panel

Purposive sampling is generally accepted as appropriate in Delphi studies as the opinion of experts is sought (Powell, 2003). However, controversy exists around definition of the term ‘expert’, who determines expertise, the size of the expert panel and whether experts are really necessary.

Sackman (1975) opposes the concept of the expert suggesting the claim to represent valid expert opinion is scientifically untenable and overstated. Additionally, Rowe et al (1991) in a review of Delphi studies found great ambiguity and inconclusiveness regarding the use of experts. A later review concluded that as most studies do not specify the characteristics of the expert group it is not possible to draw conclusions about their efficacy (Rowe & Wright, 1999). Furthermore, choosing prestigious people in the field as the expert panel may result in a halo effect (Sackman, 1975).

Pill (1971) suggests that an expert can be anyone who can contribute relevant input. McIlfatrick & Keeney (2003) support this view and propose that those who have a background and interest in a speciality should be considered expert. Others argue that knowledge and interest in the speciality does not constitute expertise (Keeney et al, 2001). It is, however, suggested that it is more appropriate to recruit individuals who have an interest in a subject and are motivated to participate rather than relying on those who have the misleading title of expert (Goodman, 1987). Those who become involved in the process are likely to be those who will be directly affected by the results and these individuals are also more likely to stay involved in the process (Keeney et al, 2001).

Selection bias is acknowledged as a disadvantage of purposive sampling. Haemato-oncology nursing is a relatively small speciality and the number of recognised experts is also small and many were known personally. To reduce the potential for selection bias all members of the Royal College of Nursing Haematology and Bone Marrow Transplant (HBMT) Forum were invited to participate in the study. Forum members have made the effort to join a professional interest group implying that they would possess knowledge of, and interest in the specialist area. It is also considered important to include practising nurses in research activity to ensure that real-world problems encountered daily are addressed through research and to help make research more relevant to practising nurses (Akinsanya, 1994).

Panel Size

As with many other features of the Delphi technique, panel size varies and optimal size has not been established. The original Delphi study recruited 7 expert participants (Dalkey & Helmer, 1963). At the opposite end of the spectrum Butterworth & Bishop (1995) involved 2006 participants. Both Delbecq et al (1975) and Rowe et al (1991) note that heterogeneous groups with widely differing personalities and perspectives produce a greater variation of acceptable solutions than homogeneous groups and suggest that experts should be recruited from varied backgrounds to guarantee a wide knowledge base. Black et al (1999) concur suggesting that as the number of people involved increases so does the reliability of the judgement. Panel size may therefore be dependent on the issue being explored and the resources available for the study. It is worth noting, however, that larger panel sizes have been associated with higher attrition rates (Dodge & Clark, 1977; Reid, 1988).

In the current study 1444 questionnaires were distributed. It is recognised that this is a large panel size but haemato-oncology although small is a diverse speciality and nurses involved in this field have different interests. A large panel would therefore increase the breadth of the knowledge base and introduce different perspectives corresponding with recommendations that participants should be recruited from a range of varied backgrounds (Delbecq et al, 1975; Rowe et al, 1991). The likelihood of high attrition rates (Dodge & Clarke, 1977; Reid, 1988) also influenced the decision to include all members of the forum in the sample as it was anticipated that those who responded to the first round were likely to be those who were motivated to participate and likely to remain involved in the study as self-nomination has been found to reduce attrition rates (Duffield, 1993; Keeney et al, 2001).

Consensus

Within a Delphi study the aim of consensus is to determine the extent to which participants agree on a particular issue (Jones & Hunter, 1995). Determining consensus is another controversial aspect of Delphi studies and studies are criticised for not stating the level of consensus at the outset (Williams & Webb, 1994). These authors claim that unless a level of consensus is stated it is moveable and can be determined at the whim of the researcher. They suggest a more reliable method is to set a numerical level either at the beginning of the research or after data analysis. Setting the level of consensus after data analysis does not, however, appear to be very reliable as the level could be manipulated by the researcher according to the results. Setting the level of consensus prior to data analysis therefore appears to be a more reliable method and is recommended as good practice (Keeney et al, 2006).

No universal agreement exists on the level of consensus. In studies identifying research priorities in health care consensus varies from 50% (Daniels & Howlett, 2001) to 100% (Williams & Webb, 1994). A great deal of time and effort has been spent thinking about and discussing consensus in the literature yet, the level of consensus continues to be an arbitrary decision with little guidance available for novice researchers (McKenna, 1994; Green et al, 1999).

Use of high consensus as a measure of agreement has also been criticised. Sackman (1975) suggests that Delphi forces consensus and penalises dissent. Several comprehensive reviews of Delphi study methodology have shown that consensus increases strongly over successive rounds and is related more to conformity to group opinion than true agreement (Woudenberg, 1991; Rowe et al, 1991; Rowe & Wright, 1999). These findings appear to threaten the reliability of Delphi study methodology as conformity to group pressure was one of the issues that the Delphi technique was designed to overcome.

In the current study cognisance was given to the arbitrary nature of consensus levels and the decision was made to set the level of consensus at the beginning of the study and replicate the consensus level set for a previous study of cancer nursing priorities (McIlfatrick & Keeney; 2003). These authors set consensus at ≥65% and found that the majority of topics gained a much greater level of consensus. As the sample in the current study is much larger than the sample in the McIlfatrick & Keeney (2003) study obtaining a level of consensus higher than 65% was thought to be unachievable. Setting consensus at a lower level could, however, be regarded as weak consensus. A consensus level of $\geq$65% was therefore set for round 2.

Iteration and Controlled Feedback

Controlled feedback occurs between rounds ensuring that all participants are aware of the group view. Iteration occurs as a result of presenting participants with controlled feedback in the form of the group response to the previous round thus allowing individuals to change their mind over successive rounds. The rationale for providing feedback is to allow the arguments of others to be considered thus encouraging issues to be viewed from new perspectives helping to inform individual judgements and enabling changes in opinion (Dalkey & Helmer, 1963; Young & Hogben, 1978). Feedback is frequently statistical in the form of ranking topics according to their median or percentage score (Goodman, 1987). The spread of results may also be examined (Rowe et al, 1991; Woudenberg, 1991).

Controversy exists about whether all results should be fed back to participants in subsequent rounds, or only those reaching consensus. It is suggested that only feeding back those opinions that reach consensus may bias results (Hasson et al, 2000). Careful consideration was given to this issue within this study and all results were fed back to the panel.

Reliability and Validity

In their original study Dalkey & Helmer (1963) concluded that further testing of the technique was required and results may be lacking in reliability. There appears to have been little attempt to further test reliability and Delphi studies are often criticised for their lack of attention to reliability and validity (Keeney et al, 2001). Reliability is, however, a difficult concept in Delphi studies. It is argued that if a Delphi questionnaire were given to different panels there would be no guarantee that results would be the same (Williams & Webb, 1994).

Interestingly, Degner et al (1987) (although not testing reliability) replicated a previous Delphi study investigating cancer research priorities undertaken by Oberst (1978) and, despite the length of time between studies and a different population found very similar results. Whether these findings can be attributed to the reliability of the data collection instrument or whether they say more about the length of time research takes to impact on nursing practice is a matter for further discussion.

Duffield (1993) also used 2 groups of expert panellists to identify competencies and test the reliability of the Delphi study. High levels of agreement were found between the 2 panels. Further research was, however, recommended to determine whether these findings demonstrated reliability or merely a lack of disagreement between the 2 groups.

Various factors may affect the validity of studies. The wording of questions is important as ambiguous statements may be interpreted differently by different individuals. Editing of responses may also affect validity as the meaning of the original statement may be changed in the editing process (Judd, 1972). In the current study respondents' original wording was used as far as possible in accordance with classic Delphi technique (Hasson et al, 2000). Although this criterion was adhered to as much as possible, in some cases editing was required to ensure clarity of the item. Clarity is important as the reliability and validity of data may be challenged if questions are not well phrased (Keeney et al, 2001). Soanes et al (2000) suggest that presenting topics in respondents' own words may have been problematic in their study making topics appear unrefined and unclear to others. Such lack of clarity has the potential to adversely affect response rates (Keeney et al, 2006). Conversely, editing may potentially introduce bias through the researcher's interpretation of the item. This potential was reduced through the use of the panel of experts in the reduction and categorisation of data. Pilot testing of questionnaires has also been suggested as a means of testing reliability (Rudy, 1996) and this was undertaken prior to round 2.

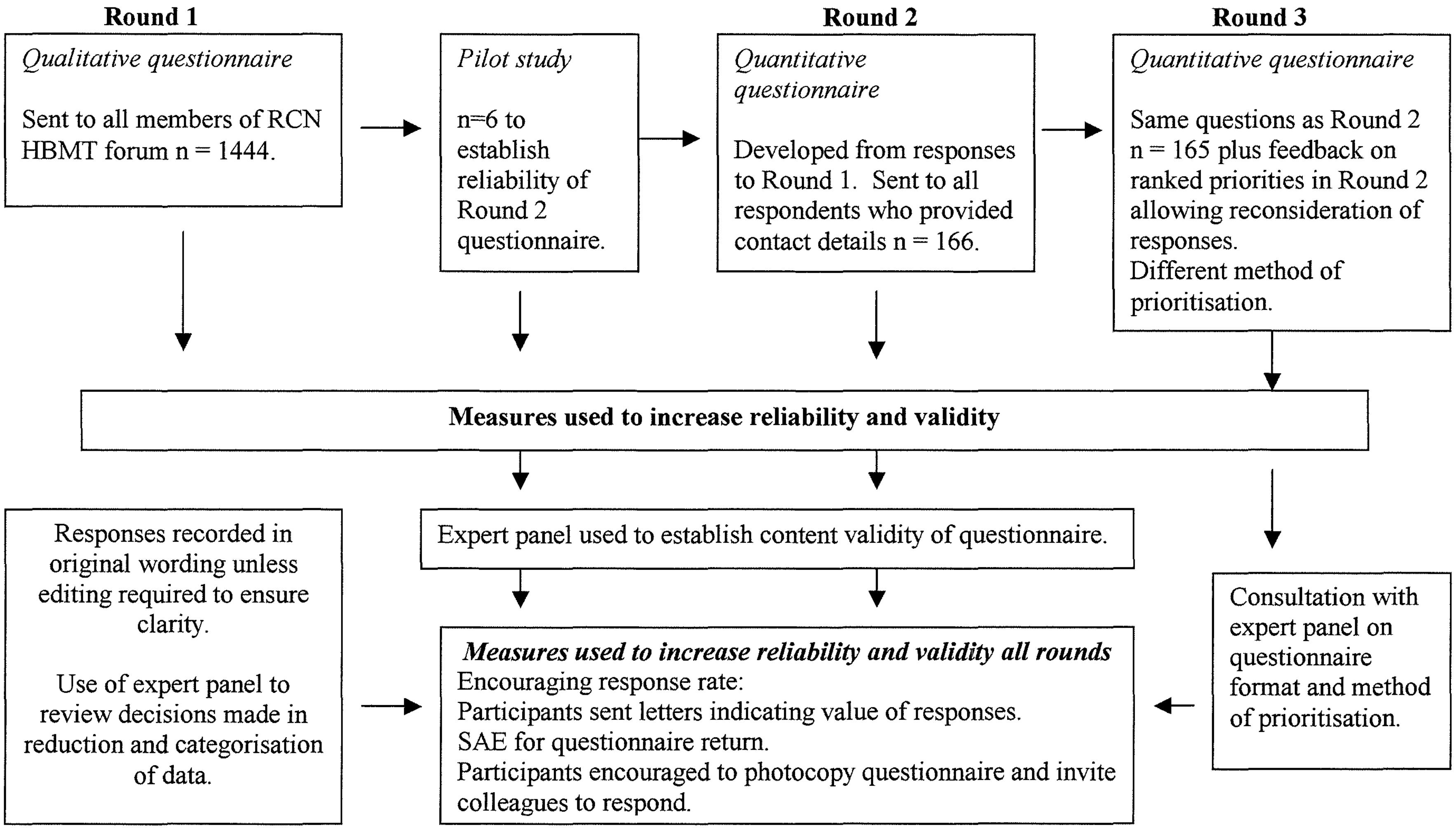
Poor response rates are a further factor affecting the validity of results. Participants therefore need to be encouraged to respond at every available opportunity (Keeney et al, 2006). In the current study various measures were taken in an attempt to maximise response rates. Letters sent to participants emphasised the value of their responses

(Appendices 6, 7 & 8). Participants were also asked to photocopy the questionnaire and invite their colleagues to complete it. Additionally, participants were also asked to add their name and contact address to the completed questionnaire if they were willing to contribute to subsequent rounds. As names and addresses of participants were known in subsequent rounds a follow up letter and further copy of the questionnaire was sent to those who had not already responded 2 weeks before the identified deadline.

Fink et al (1984) suggest that a clear decision trail should be evident to overcome some of the difficulties associated with determining reliability and validity. Researchers should be able to defend their decisions for the techniques used to ensure credibility of findings. This should include: defending the method chosen, the rationale for choice of expert panel, data collection procedures, identification of consensus and means of dissemination and implementation.

Every effort has been made to ensure that the processes used in conducting this Delphi study are well described, open and transparent (Figure 1). Using more than one researcher to analyse results independently and feeding back responses to participants and checking that they have been interpreted correctly by the researcher are useful means of determining credibility (Lincoln & Guba, 1985). Use of an expert panel is also thought to result in high content validity (Goodman, 1987). In this study, two experienced researchers (one of whom is also a recognised expert in haemato-oncology) and a further recognised expert in haemato-oncology were asked to review the decisions made on reduction and categorisation in round one and development of subsequent questionnaires thus establishing content validity and interrater reliability (Mead & Moseley, 2001a).

Figure 1: Overview of Research Design and Approaches to Reliability and Validity



Qualitative questionnaire

Sent to all members of RCN HBMT forum n = 1444.

Pilot study

n=6 to establish reliability of Round 2 questionnaire.

Quantitative questionnaire

Developed from responses to Round 1. Sent to all respondents who provided contact details n = 166.

Quantitative questionnaire

Same questions as Round 2 n = 165 plus feedback on ranked priorities in Round 2 allowing reconsideration of responses.
Different method of prioritisation.

Measures used to increase reliability and validity

Responses recorded in original wording unless editing required to ensure clarity.

Use of expert panel to review decisions made in reduction and categorisation of data.

Expert panel used to establish content validity of questionnaire.

Measures used to increase reliability and validity all rounds
Encouraging response rate:
Participants sent letters indicating value of responses.
SAE for questionnaire return.
Participants encouraged to photocopy questionnaire and invite colleagues to respond.

Consultation with expert panel on questionnaire format and method of prioritisation.

Data Collection Methods

Round 1

A questionnaire adapted from the work of Browne et al (2002) was designed comprising demographic questions and asking respondents to list in order of priority "the three most important questions or problems relating to haemato-oncology nursing that you consider should be researched".

Demographic data were included as variables such as workplace, the length of time respondents had worked in the speciality and their role in direct patient care could have had an impact on the results obtained. These data can also be used to determine the expertise and knowledge of participants. Browne et al's (2002) study asked for five priorities to be listed. However, after discussion with the lead researcher for this study it was decided to limit to 3 priority areas due to the potentially large volume of data that could be returned. Diversity of opinion is characteristic of the first round of Delphi studies and it is well recognised that the amount of data generated can be enormous and unwieldy (McKenna, 1994; Procter & Hunt, 1994; Keeney et al, 2001).

A letter inviting participation in the Delphi study, the first questionnaire and a stamped addressed envelope for return of the questionnaire were included with the RCN HBMT Forum's newsletter in January 2004 (Appendix 4).

Pilot Study

Research topics identified by participants in round 1 were used to compile the questionnaire for round 2. A pilot study was undertaken with 6 nurses from the local haemato-oncology unit, who were not involved in the study to establish reliability of the questionnaire and determine how long it would take to complete, clarity of instructions, format of the questionnaire and any difficulties experienced in completion. Following the pilot study the questionnaire was adapted before distribution in round 2.

Round 2

All respondents who provided their contact details in round one were sent a questionnaire. Respondents were asked to rank research priorities on a graphic rating scale rated with 1 being low and 7 being high (Appendix 5). Mead and Moseley (2001b) suggest that 7 is an appropriate number for such scales. Anything less and there is little scope for fine judgements and above 7, numbers exceed human capacity for retaining topics in short-term memory. Following analysis of results from the second round the decision was subsequently made to undertake a third round and participants were given a second opportunity to prioritise the identified research topics.

Round 3

All respondents for whom contact details were available were sent a round 3 questionnaire, irrespective of whether they had responded to round 2. Participants were also sent feedback detailing ranked priorities from round 2 (Appendix 6). Respondents were therefore able to re-evaluate their views and reconsider their responses in the light of the responses of others (Rowe et al, 1991; Beretta, 1996). The round 3 questionnaire contained the same questions as the round 2 questionnaire but the method of prioritisation differed. Respondents were asked to identify the first, second and third research priorities in each category.

Data Analysis

Data analysis took place between each round. Demographic data were entered into the computer package (Statistical Package for Social Sciences) SPSS. Research priorities identified in the first round were also entered verbatim into SPSS. Although this package is not intended for qualitative data it allowed each respondent and research priority to be given an identification code prior to the processes of content analysis, data reduction and categorisation. The amount of data generated in the first round makes reduction and categorisation usual at this stage (Mead & Moseley, 2001a). Content analysis and reduction of data were conducted and categories identified. All topics identified by respondents were placed in an Excel spreadsheet in one of the identified categories.

Data from the second and third rounds were analysed using descriptive statistics. The median of the topics and distribution of responses across the rating scales were also examined. Statistical aggregation and summary of group response are common means of analysing data in Delphi studies from second and subsequent rounds (Wilhelm, 2001). Descriptive and inferential statistics usually measures of central tendency and measures of dispersion e.g. interquartile range are frequently used (Rowe & Wright, 1999; Hasson et al, 2000).

Consistency of response between rounds 2 and 3 was also examined. Scheibe et al (1975) contend that examination of stability of responses allows much more information to be obtained from a study while preserving opinion distributions. A variety of statistical tests are suggested to measure stability (Dajini et al, 1979). These were all considered inappropriate in this instance because of the different methods used to prioritise topics in rounds 2 and 3. Topics that were consistently highly rated in both rounds were therefore explored.

Ethical Issues

With any research project ethical issues require to be considered. Protecting the individual by ensuring confidentiality and anonymity, informed consent, the right to participate voluntarily and minimising the risk of harm to participants are major ethical considerations (Burns & Grove, 2003). Participants were initially approached through a newsletter from a professional forum ensuring that no names or addresses were released to the researcher thereby maintaining confidentiality and complying with the Data Protection Act (1998). In completing the first and subsequent questionnaires participants voluntarily included their names and addresses if they were willing to be involved in subsequent rounds. The inclusion of names and addresses means that respondents were known to the researcher.

Anonymity of responses is considered a particular challenge in relation to Delphi studies (Beretta, 1996; Keeney et al, 2006). Guaranteeing anonymity is perceived as difficult as individual responses although not known to other participants are known to the researcher (McKenna 1994; Keeney et al, 2006). McKenna (1994) refers to this as quasi-anonymity. This position is, however, not unique to Delphi studies and is also an issue in qualitative research particularly studies with small sample sizes where responses can be attributed to an individual and are easily identifiable by the researcher. In this study each respondent was allocated a code known only to the researcher. In this way individual responses could be identified from the original data set, however, the size of the data set precluded identification of individuals once data were entered. Anonymity was therefore preserved. Apart from the researcher no-one else had access to respondents details or their responses thus ensuring confidentiality and anonymity. All data were stored in a locked drawer to which only the researcher had access therefore ensuring security of data.

Informed consent based on the ethical principle of autonomy and the right of individuals to make informed decisions is a further important ethical principle (Gillon, 1994). The process of informed consent is based on having sufficient objective information on which to base a decision, the right to withdraw or refuse to participate in research without any detriment to self (RCN, 2003). In this study, letters to participants clearly stated what the study involved and what was expected of participants. Participants voluntarily included their names and addresses on returned questionnaires stating they were willing to be involved in further rounds of the study and this was interpreted as implicit consent. This assumption could perhaps be questioned as it is suggested that nurses may not be aware that they can refuse to participate in research (Griffiths, 2006). Yet, given the number of non-respondents in the first round of this study this lack of awareness appears unlikely.

Anonymity is also associated with informed consent. As the researcher knows the contact details of participants reminder letters could be sent if questionnaires were not returned. Yet, reminder letters may be perceived as placing pressure on participants to complete the questionnaire when a lack of response may indicate that they wish to withdraw from the study (Beretta, 1996). Conversely, a reminder letter is a recognised means of increasing response rates to questionnaires (Polit & Hungler, 1991). A balance therefore needs to be maintained between the need to maximise response rates to increase the validity of study results with the potential for harm to participants incurred through placing undue pressure on them to respond. Ethical decision making is based on consideration of the ethical principles involved leaving considerable scope for making judgments (Cerinus, 2001). The risks of harm to participants therefore have to be balanced against the benefits and value of the research (Cerinus, 2001). Sending reminder letters to increase response rate is common in questionnaire and survey research and in considering the issues it appeared unlikely that one reminder letter would be interpreted as undue pressure.

Anonymity also allows participants to respond objectively without being influenced by other participants (Goodman, 1987). It is, however, acknowledged that in a Delphi study participants may be known to each other as work colleagues may have discussed responses and feel pressurised to respond in a certain way (Keeney et al, 2001). Certainly, in the current study some respondents worked in the same place and may have discussed their responses with one another. The impact of the influence of other participants in a Delphi study has, however, not been researched and remains unknown. Yet, the potential for such coercion is much less in a Delphi study than in other face-to-face methods of gaining consensus (Mead & Moseley, 2001a). Furthermore, the potential adverse influence also needs to be balanced against the positive impact of knowing other participants which may result in increased response rate (Keeney et al, 2006). An increased response rate will increase the value and credibility of the study with the potential to benefit patients and other health care professionals through dissemination of results. Furthermore, the contribution of participants to the research process was acknowledged between rounds and they were informed of results between rounds of the study. These benefits were perceived to outweigh the risks.

Ethical approval for the study was sought through the local health services research ethics committee who categorised the project as an audit and stated that ethical approval was not required (Appendix 7).

Conclusion

A discussion and analysis of the different research methodologies that could have been used to identify research priorities has been undertaken. As insufficient information was available to determine priority research topics in haemato-oncology nursing a mixed methodology combining an initial qualitative approach to identifying research priorities followed by a quantitative approach to determine the perceived importance of each priority was considered to be most appropriate for this study. Following exploration of the different research methodologies used for determining consensus, the Delphi technique was decided upon for this study as it was considered to be best means of gathering information on the topics a geographically diverse group of practising haemato-oncology nurses regarded as research priorities.

No universal guidelines exist for several aspects of the Delphi technique including the number of rounds, panel size, criteria for determining expertise and determining consensus. Decisions therefore have to be made in the context of the individual study and have led to criticisms relating to the rigour of the technique. The decisions made in planning this study were therefore crucial to the credibility of the subsequent research and achieving the aim of advancing knowledge for haemato-oncology nursing practice. This chapter has outlined the rationale for decisions made in the context of this study with particular attention being given to panel size, defining expertise and determining consensus. Furthermore, great consideration was given to reducing the attrition rate between rounds and enhancing the reliability and validity of results.

It is, however, recognised that the Delphi technique is an iterative process as each round of the Delphi technique builds on the results of the previous round. Decisions made in planning the study may therefore need to be revised as the study evolves. Decisions made in the process of undertaking the study are discussed in relation to the results of each round in the subsequent chapter.

CHAPTER 6: RESULTS

Introduction

It is recognised that a Delphi study has the potential to generate vast amounts of data (McKenna, 1994; Procter & Hunt, 1994; Keeney et al, 2001) and this study was no exception. Due to the large amounts of data produced the major themes emerging from the 3 rounds of the Delphi study are presented and discussed. As acknowledged in chapter 5 the Delphi technique is an iterative process (McKenna, 1994) and decisions made both in and between rounds are also discussed.

Response Rates

Round 1

A total of 249 questionnaires were returned, a 17% response rate. Six were returned unanswered and 8 were incomplete. Three of the latter questionnaires contained contact details and respondents were sent a further questionnaire. None of these was returned. Contact details were, however, retained for the second round. A further 5 questionnaires were damaged and unusable. The remaining 230 questionnaires (16% response rate) were included in the analysis.

Only 166 respondents (11.5%) included their contact details stating they were willing to participate in round 2. The sample size for round 2 was therefore considerably reduced. It is, however, suggested that those who are particularly interested in a topic and self-nominate are more likely to stay involved (Duffield, 1993; Keeney et al, 2001). As respondents had already indicated their interest in the study by volunteering for the second round it was anticipated that they would stay involved.

Round 2

From the 166 questionnaires distributed, 119 were returned, a 72% response rate. The high response rate supported the notion that those who had volunteered for the second round were interested and likely to stay involved in the study. A total of 116 questionnaires (70%) were included in the analysis as 3 incomplete questionnaires were excluded.

Round 3

From the 165 questionnaires distributed 115 (70%) were returned. Eleven questionnaires were returned unanswered and a further questionnaire was excluded as it was completed incorrectly. A total of 103 completed questionnaires (62%) were included in the analysis. The attrition rate between rounds 2 (119 responses) and 3 was extremely small (4%) further supporting the idea that interested individuals remain involved. Further analysis, however, revealed differences in respondents between rounds. Thirty seven respondents participated in round 2 but not round 3 and 24 respondents who participated in round 3 did not participate in round 2. A total of 79 respondents participated in both rounds. These figures suggest that individual attrition rates between rounds are larger than depicted perhaps indicating questionnaire fatigue. Yet, some participants responded in round 1 and round 3 but not round 2. Reasons for this are unclear but it does appear to negate the previous comment regarding questionnaire fatigue. The new respondents in round 3 are likely to be a positive response to the request for respondents to photocopy the questionnaire and encourage their colleagues to participate.

Demographic Data

Country of Work

Demographic data from the 3 rounds of the study were very similar and are therefore presented together. The majority of respondents worked in England (mean 80% (n=181), range 77.7-82.1% (n=80-184)). Much smaller numbers worked in Scotland (mean 8.7% (n=13), range 7.7-9.7% (n=9-20)), Wales (mean 6.8% (n=9.3), range 4.8-7.8% (n=8-11) and Northern Ireland (mean 2% (n=3), range 1.7-2.6% (n=2-4)) (Table 1). Two respondents were working overseas one in Uganda and, in the third round, one respondent had moved to Australia. The higher response rate from England is not surprising as it is larger and has a greater number of haemato-oncology units than other UK countries. It is possible that the greater number of responses from England may have biased responses as research priorities in the other UK countries may have been different. It was not possible to explore this further statistically as the small number of responses from the other 3 countries made it impossible to correlate responses.

Table 1: Country of Work

Country of Work	Round 1		Round 2		Round 3	
	No. of nurses	Percentage	No. of nurses	Percentage	No. of nurses	Percentage
England	184	80	96	82.1	80	77.7
Scotland	20	8.7	9	7.7	10	9.7
Wales	11	4.8	9	7.7	8	7.8
Northern Ireland	4	1.7	3	2.6	2	1.9
Uganda	1	0.4	-	-	1	1
Australia	-	-	-	-	1	1
Missing	10	4.3	-	-	1	1

Place of Work

Across the 3 rounds the mean number of respondents working in dedicated haemato-oncology areas was 51% (n=227) (range 46.2-52.4%). These areas included both inpatient and outpatient areas and BMT and non-BMT areas (Table 2). A further 3.6% (n=12) worked in specialist paediatric haemato-oncology areas. Substantial numbers (mean 33% (n=62)) were also working in areas where haemato-oncology was combined with another speciality, most frequently oncology. Smaller numbers of respondents were working in related education or research areas. The majority of respondents were working in the speciality and therefore well placed to identify relevant research priorities. The spread of respondents working in different haemato-oncology areas also reduced the potential for focusing on one particular area for example BMT and increases the potential for identifying research priorities across the spectrum of the speciality.

Table 2: Place of Work

Place of work	Round 1		Round 2		Round 3	
	No. of nurses	Percentage	No. of nurses	Percentage	No. of nurses	Percentage
Haematology inpatient area (Non-BMT)	15	6.5	3	2.6	12	11.7
Haem outpt/day area	29	12.6	11	9.4	11	10.7
Combined haem/BMT unit	49	21.3	25	21.4	20	19.4
BMT unit	7	3	4	3.4	4	3.9
Combined haem inpt/outpt	19	8.2	11	9.3	7	6.8
Paediatric haem/oncology	5	2.2	3	2.6	4	3.9
Combined haem/oncology/ palliative care	54	23.5	35	29.9	22	21.4
Combined haem/other medical speciality	21	9.1	11	9.4	5	4.9
Education	6	2.6	5	4.3	7	6.8
Cancer research/trials	2	0.9	2	1.7	1	1
Community	2	0.9	1	0.9	1	1
Critical care	1	0.4	1	0.9	1	1
Palliative care	2	0.9	2	1.7	1	1
Oncology	2	0.9	-	-	2	1.9
Others	12	5.2	2	1.7	2	1.9
Missing	4	1.7	1	0.9	3	2.9

Role and Experience

The majority of respondents (mean 77%, range 74.7-80.8%) were working directly with patients either as clinical nurses, combined clinical nurse/ward manager or clinical nurse specialists (Table 3). Most respondents were also experienced haemato-oncology nurses who had worked in the speciality for over 5 years (mean 77.5%) (Table 4). The experience of working in haemato-oncology for such long periods of time suggests that respondents would have a good grasp of patient needs and problems, increasing their awareness of potential research priorities.

Table 3: Role

Role	Round 1		Round 2		Round 3	
	No. of nurses	**Percentage**	**No. of nurses**	**Percentage**	**No. of nurses**	**Percentage**
Clinical nurse	92	40	42	35.9	30	29.1
Combined clinical nurse/ward manager	44	19.1	23	19.7	21	20.4
CNS	50	21.7	23	19.7	26	25.2
Manager	11	4.8	9	7.7	7	6.8
Lead cancer nurse	-	-	1	0.9	1	1
Consultant Nurse	2	1	-	-	-	-
Matron cancer services	-	-	2	1.7	2	1.9
Research nurse	5	2.2	4	3.4	-	-
Researcher	5	2.2	2	1.7	2	1.9
Educationalist	14	6.1	9	7.7	11	10.7
BMT coordinator	3	1.3	-	-	-	-
Others	4	1.6	2	1.7	2	1.9
Missing	-	-	-	-	1	1

Table 4: Experience

No. of years working in haematology	Round 1		Round 2		Round 3	
	No. of nurses	**Percentage**	**No. of nurses**	**Percentage**	**No. of nurses**	**Percentage**
1-5	68	29.6	29	24.8	13	12.6
6-10	71	30.9	43	36.8	33	32
11-15	59	25.7	28	23.9	37	35.9
16-20	25	10.9	14	12	14	13.6
21-25	4	1.7	2	1.7	4	3.9
Over 25 years	2	0.9	-	-	2	1.9
Missing	1	0.4	1	0.9	-	-

Qualifications

Respondents were well qualified with the majority holding a post registration qualification (mean 90.2%, range 88.1-91.3%) (Table 5). The most common levels of post-registration qualification were diploma (mean 37.5%, range 36.9-38.5) and degree (mean 38.5%, range 38.3-38.8). Fewer respondents held a masters level qualification (mean 9.8%) although these numbers showed an incremental increase throughout the study and had doubled by the third round (range 6.5-13.6). A number of respondents also indicated that they were working towards either a degree or masters level qualification. The majority of respondents (mean 79.3%, range 67.8-87.4%) had a specialist oncology or haemato-oncology qualification with a mean of 39.1% (range 31.3-47.5%) having completed specialist haemato-oncology or BMT courses (usually the former English National Board courses). The qualifications of respondents combined with the large numbers working in direct contact with patients and the longevity of their experience suggest that respondents are likely to have the requisite knowledge and experience to identify relevant research priorities.

Table 5: Qualifications

Post-registration qualifications	**Round 1**		**Round 2**		**Round 3**	
	No. of nurses	**Percentage**	**No. of nurses**	**Percentage**	**No. of nurses**	**Percentage**
Diploma	85	37	45	38.5	38	36.9
Degree	88	38.3	45	38.5	40	38.8
Post-graduate diploma	1	0.4	2	1.7	2	1.9
Masters	15	6.5	11	9.4	14	13.6
No post-registration qualification	5	2.2	14	12	9	8.7
Missing	36	15.7	-	-	-	-

Research Priorities

Round 1

The questionnaires yielded 517 research priorities. Only 50 (10%) were identified more than once. Topics identified were reduced and organised into categories. Areas of overlap were identified and similar topics clustered together and collapsed to form one topic. Topics containing more than one theme were split into 2 or more elements. Mead & Moseley (2001a) suggest this is appropriate because if statements with multiple themes are allowed in a subsequent round it is difficult to determine which element of the statement is viewed as important.

A number of topics were excluded from further analysis as they were not perceived to be appropriate to adult haemato-oncology nursing research. These topics were encompassed in 4 broad categories; topics that were unclear, research more appropriate for other health care professionals, paediatric issues and responses not related to haemato-oncology for example breast cancer and sickle cell disease. The remaining 199 topics were arranged in 10 categories and presented as either research questions or statements to retain their original presentation by respondents and avoid changing the meaning of the original statement.

The decision trail for reduction and categorisation was reviewed by the expert panel. Responses suggested some minor rearrangements of topics and increasing the number of categories as some were rather lengthy. Topics were reorganised into 11 categories:

1. Education
2. Service Delivery and Organisation of Care
3. Effects of Role on Nurses' Health and Support Needs
4. Communication/Patient Information and Education
5. Ethical Decision Making
6. Nurses' Role
7. Utilising Knowledge and Developing the Evidence Base for Practice
8. Nursing Interventions and Care
9. Symptom Management
10. Psychosocial Wellbeing and Support
11. Patient and Family Experience

A second draft questionnaire was returned to the expert panel for comment. Responses from the panel suggested some minor suggestions for rearranging topics. Some overlap was also identified and subsequently several topics were amalgamated reducing the number in the questionnaire to 178.

Many topics identified within these categories appeared to be more appropriate to education than research. Previous Delphi studies have also reported responses which implied a lack of awareness of previous research or relevant literature (Hagan & Hunt, 1998; Daniels & Ascough, 1999; Soanes et al, 2000; Daniels & Howlett, 2001). However, Hagen & Hunt (1998) found on probing that different aspects of the topic that had not been previously researched were actually being identified. For these reasons a pilot study was conducted to determine the feasibility of incorporating both education and research into the second questionnaire. The pilot study questionnaire is included in Appendix 8.

Pilot Study

Respondents were asked to consider the 2 questions below and rate each topic on a 7 point graphic rating scale:

1) How important is this topic to haemato-oncology nursing research?
2) How important is this topic to haemato-oncology nursing education?

Five of the six questionnaires were returned. The pilot questionnaire took between 30 minutes and 1½ hours to complete with a mean of 53 minutes. This time was considered to be far too long for the main study as it appeared unlikely that many participants would be willing to complete a questionnaire of that length. Four respondents indicated that the questionnaire was difficult to complete with the remaining respondent suggesting somewhere between easy and difficult. All respondents stated that the instructions for completing the questionnaire were clear although one respondent appeared to misinterpret what was expected and tried to provide answers to the research questions. Three respondents found the format unclear and 2 clear. Further comments suggested that lack of clarity was due to the number of questions/statements and difficulties in rating them in terms of importance for both research and education.

Discussion with respondents indicated that removing the educational element from the questionnaire would improve clarity and the decision to remove this element was taken. Removing the education component would also reduce the length of time required to complete the questionnaire. Exploring education as well as research priorities would have been informative but was not the primary objective of the study and obviously too much for one questionnaire. It would, however, be interesting to undertake a similar exercise relating to education in the future.

Round 2

Each topic on the questionnaire was ranked according to the sum of 6 and 7 scores (high priority) and reported as a percentage. Scores of 6 and 7 were used to ensure that topics identified as priorities were those rated highly and not due to an accumulation of many low scores. Fifty topics (28%) reached the preset level of consensus of ≥65%. The top 10 highest rated priorities covered a diverse range of research topics and included topics from 8 of the 11 categories. The scores awarded to the top 10 priorities were very closely clustered with the highest rated priority scoring 81.2% and topics rated tenth scoring 72.7% (range 8.5%). Furthermore 2 topics tied for fourth place and 5 topics tied for tenth place (Table 6). Due to the narrow range of scores the top 10 priorities included 12 topics.

Further analysis of data demonstrated small differences between scores in all topics reaching consensus. Between the top 10 and the top 50 topics, 9 sets of tied scores were demonstrated. No single topic had a score that was not shared with at least one other topic and one set of tied scores included 7 topics. The complete list of ranked priorities is shown in Appendix 9.

Table 6: Top 10 Priorities

Topic	Category	Percent
1) Patients' & relatives' views on the information and support they receive regarding diagnosis & treatments	Communication, patient information and education	81.2
2) Long term health risks of nurses exposed to chemotherapy/antibiotics	Effects of role on nurses' health and support needs	80.3
3) What is nurses' knowledge of neutropenic sepsis?	Education	77.8
4) Are nurse shortages detrimental to practical/emotional support?	Service delivery and organisation of care	75.2
4) What do patients expect/require from nurses?	Patient & family experience	75.2
6) Making decision when active treatment ends & palliative treatment begins	Ethical decision making	74.4
7) Access to haematological nurse education/ courses	Education	73.5
10) When to actively treat and when to withdraw treatment	Ethical decision making	72.7
10) How can chemotherapy training & administration be standardised throughout the UK?	Education	72.7
10) Management and care of neutropenic patients	Nursing interventions/care	72.7
10) Psychological effects of relapse for the patient and family	Patient & family experience	72.7
10) How effective/successful are nurse led services?	Nurses' role	72.7

The close clustering of scores indicated a lack of differentiation between priorities. Clustering of responses on a rating scale is noted to be problematic as discrimination is lost if only a few points on the scale are used (Mead & Moseley, 2001b). If everything is a priority then there are no priorities. Further examination of responses substantiated a lack of discrimination between topics. Most topics were rated 5-7 and across the entire questionnaire only 18% of responses were rated 4 or less (Table 7). The median of all topics ranged from 4 to 7 but the majority had a median of 6 (n=133) demonstrating a definite clustering of responses at the top end of the rating scale (Appendix 9).

Table 7: Distribution of Responses Across Rating Scale

Rating	Number of responses	Percentage of responses
1	125	0.6
2	244	1.2
3	813	3.9
4	2492	12.1
5	5007	24.3
6	6614	32.1
7	5313	25.8

Further statistical analysis was undertaken with the Chi-square test (df=6) which indicated the estimated number of responses if all values on the 7 point scale had been scored an equal number for times (Table 8). A significant lack of uniformity was demonstrated across the scale. Values 1-3 showed a significant deficit in the anticipated number of responses while values 5-7 showed a significant increase. These results were significant at the level of $p<0.0005$. Responses to value 4 on the rating scale were closest to the expected percentage of 14.3% if all values on the 7 point scale had been scored an equal number of times.

Table 8: Chi-square Test Demonstrating Lack of Uniformity Across Rating Scale

Score	Observed Number	Expected Number	Residual
1	125	2944	-2819
2	244	2944	-2700
3	813	2944	-2131
4	2492	2944	-452
5	5007	2944	2063
6	6614	2944	3670
7	5313	2944	2369
Total	20608		

Results indicated that respondents had difficulty in prioritising between topics and demonstrate a lack of clear consensus. This lack of consensus and discrimination between priorities influenced the decision to undertake a third round of the study.

Deadlines for publication of the textbook precluded a third round before the manuscript was submitted for publication. The first 2 rounds only are therefore presented in the textbook.

Round 3

Method of Prioritisation

In a classic Delphi study the round 3 questionnaire is exactly the same as the round 2 questionnaire (Delbecq et al, 1975). The lack of discrimination between topics in round 2 indicated that little would be gained from using the same questionnaire again. Two further options were therefore considered. Option 1 was to create a new questionnaire from the 50 topics that reached consensus and ask respondents to rate them on a 7 point rating scale. I had reservations about this option as it used the same rating scale as round 2 and the potential for the lack of discrimination between topics to be repeated appeared high. Furthermore, Williams & Webb (1994) argue that omitting items from a Delphi study is likely to increase attrition as respondents may not choose to complete a subsequent questionnaire if they find that their original contribution has not been included.

Option 2 was to use the same questionnaire employed in round 2 but change the method of prioritisation to aid discrimination between topics. Respondents would be asked to identify the top 3 priorities in each of the 11 categories. Following consultation with the expert panel the latter option was chosen.

Round 3 Results

First Priorities

None of the topics rated as first priorities reached the ≥65% level of consensus set for round 2. This is not surprising as in round 2 respondents were asked to rate every topic rather than choose 3 from each category. The number of potential scores for each topic was therefore greatly reduced in round 3. Exploring the scoring within categories was therefore a more accurate way of determining agreement between rounds.

Within categories, comparison of results from rounds 2 and 3 demonstrated remarkable consistency. In all categories the highest rated first priority topic in round 3 corresponded to highest rated topic in each category in round 2 (Table 9). In the category 'service delivery and organisation of care' 2 topics tied as the first priority corresponding with the first and second highest ranked topics in this category in round 2. In all categories, the round 3 highest rated first priority topics also reached the predetermined level of consensus in round 2. This high level of agreement between rounds increases the credibility of these topics as research priorities.

Table 9: Comparison of Most Highly Rated First Priorities in Each Category in Round 3 to Round 2 Results

Category	Topic	Score Round 3 (%)	Rank in Category Round 2
Symptom management	How can the side-effects of chemotherapy be reduced?	50.5	1
Communication/patient information and education	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	46.6	1
Nursing interventions and care	Management and care of neutropenic patients	46.6	1
Effects of role on nurses' health and support needs	Long term health risks of nurses exposed to chemotherapy/antibiotics	44.7	1
Ethical decision making	Making decision when active treatment ends and palliative treatment begins	32	1
Psychosocial wellbeing & support	Quality of life – what does it really mean to the patient?	32	1
Nurses' role	How effective/successful are nurse led services?	29.1	1
Education	What is nurses' knowledge of neutropenic sepsis?	28.2	1
Patient & family experience	What do patients expect/require from nurses?	28.2	1
Utilising knowledge and developing the evidence base for practice	What is best practice in protective isolation care? Is there a best practice?	27.2	1
Service delivery and organisation of care	What is the effect of staffing levels and skill mix on outcomes of care?	16.5	2
	Are staff shortages detrimental to practical/emotional support?	16.5	1

In 10 of the 11 categories clear discrimination in scores is demonstrated between the highest rated first priority topics and all other topics (Table 10 and Appendix 10). In the remaining category 'service delivery and organisation of care' scores were divided between the 2 topics that tied for first place. It is therefore not surprising that these scores were much lower than the highest rated first priority scores in the other categories. There is also a smaller gap between the highest rated first priority topics and the subsequent topic in this category.

Table 10: Top 3 First Priority Scores by Category

Category	Top 3 first Priorities	%
Education	What is nurses' knowledge of neutropenic sepsis?	28.2
	How can chemotherapy training & administration be standardised throughout the UK?	20.4
	Is depth of knowledge of nurses administering chemotherapy sufficient?	9.7
Service Delivery & Organisation of Care	What is the effect of staffing levels & skill mix on outcomes of care?	16.5
	Are staff shortages detrimental to practical/emotional support?	16.5
	Transition from curative to palliative care & treatment	14.6
Effects of Role on Nurses' Health and Support Needs	Long term health risks of nurses exposed to chemotherapy/antibiotics	44.7
	What are the psychological support needs of nurses & other health care professionals?	14.6
	Is effective clinical supervision available to nurses in haemato-oncology?	13.6
Communication/ Patient Information and Education	Patients' & relatives' views on the information and support they receive regarding diagnosis and treatments	46.6
	Effect of communication good/bad on patients	11.7
	Breaking bad news. Who does the patient prefer, nurses or doctors?	7.8
Ethical Decision Making	Making decision when active treatment ends and palliative treatment begins	32
	When to actively treat and when to withdraw treatment	21.4
	Does the patient receive sufficient information to provide informed consent?	18.4
Utilising Knowledge and Developing the Evidence Base for Practice	What is best practice in protective isolation care? Is there a best practice?	27.2
	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	21.4
	Clear guidelines on mucositis management	11.7
Nursing Interventions and Care	Management and care of neutropenic patients	46.6
	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	9.7
	How can prevention of infection measures be improved?	9.7
Symptom Management	How can the side-effects of chemotherapy be reduced?	50.5
	Disease and treatment related fatigue	18.4
	Management of GVHD treatment complications	8.7
Psychosocial Wellbeing & Support	Quality of life - What does it really mean to the patient?	32
	What are the psychosocial support needs of patients with haematological cancers & their families?	12.6
	How could nurses improve support for patients?	8.7
Patient & Family Experience	What do patients expect/require from nurses?	28.2
	How important to patients is access to a CNS?	8.7
	Effect of low staff morale and staffing on experiences of isolated patient	7.8
	Psychological effects of intensive treatment on patients & families	7.8
Nurses' Role	How effective/successful are nurse led services?	29.1
	Critical care skills are they an essential requirement for haematology/ BMT nurses?	18.4
	Do haematology patients with malignant disease get sufficient specialist nurse support?	12.6

Second Priorities

Slightly less consistency is apparent for second priorities between rounds 2 and 3 (Table 11). Six of the round 3 highest rated second priority topics were also ranked second in their category in round 2. A further 2 topics were ranked first and 3 topics were ranked third. The remaining highest rated second priority 'how effective is the CNS role in haemato-oncology?' in the category 'nurses' role' was ranked fifth in the category in round 2. With the exception of the latter topic all of the most highly rated second priorities were included in the 3 highest ranked topics in their respective categories in round 2.

In 3 categories, 'service delivery and organisation of care' 'utilising and developing the evidence base for practice' and 'patient and family experience' the highest rated second priorities were also the most highly rated first priority. All of the highest rated second priority topics in round 3 also reached the predetermined level of consensus in round 2 demonstrating good agreement between rounds.

Table 11: Comparison of Most Highly Rated Second Priorities in Each Category to Second Round Results

Category	**Topic**	**Score Round 3 (%)**	**Rank in Category Round 2**
Symptom Management	Disease and treatment related fatigue	26.2	2
Service Delivery and Organisation of Care	What is the effect of staffing levels & skill mix on outcomes of care?	21.4	2
Effects of Role on Nurses' Health and Support Needs	Psychological effects on health care professionals working in BMT/haematology	21.4	2
Ethical Decision Making	When to actively treat and when to withdraw treatment	19.4	2
Communication/Patient Information and Education	Effect of communication good/bad on patients	18.4	2
Education	How can chemotherapy training & administration be standardised throughout the UK?	17.5	3
Nursing Interventions and Care	How can prevention of infection measures be improved?	16.5	2
Nurses' Role	How effective is the CNS role in haemato-oncology?	15.5	5
Utilising Knowledge and Developing the Evidence Base for Practice	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	14.6	3
	What is best practice in protective isolation care? Is there a best practice?	14.6	1
Psychosocial Wellbeing & Support	What are the psychological support needs of patients with haematological cancers & their families?	12.6	3
Patient & Family Experience	What do patients expect/require from nurses?	12.6	1

In 10 categories clear discrimination is demonstrated between the scores for the highest rated second priority and all other topics in that category (Table 12 and Appendix 11). In the remaining category 'utilising knowledge and developing the evidence base for practice' 2 topics tied for first place thereby reducing the score in comparison to those in other categories. The gap between the first and second highest rated topics in each category does, however, tend to be smaller than the gap between first priority topics.

Third Priorities

Slightly over half (6) of the top third priority topics in each category were included in the first 3 priorities in their respective categories in round 2 (Table 13). Other top third priority topics were not always rated particularly highly in their categories in round 2 and were placed fourth, fifth, sixth and eighth (last). Less discrimination also exists between the 3 highest rated third priorities with tied places in 7 categories (Table 14 and Appendix 12). Yet, despite this apparent lack of agreement between rounds only 2 of the round 3, top third priority topics ('availability of training and support and effect on stress development' and 'how can end of journey decision making with patients be improved?') did not reach the predetermined level of consensus in round 2.

In 2 categories (education and service delivery and organisation of care) the most highly rated third priorities were also the most highly rated first priorities. Additionally, the highest rated third priority in the symptom management category was also the highest rated second priority in that category. In all categories the same topics appeared more than once in the top 3 first, second and third priorities (Appendix 13). The frequency of their overall occurrence was therefore explored further.

Table 12: Top 3 Second Priority Scores by Category

Category	Top 3 second Priorities	%
Education	How can chemotherapy training & administration be standardised throughout the UK?	17.5
	How can high standards /levels of knowledge in cytotoxic administration be maintained?	15.5
	Is depth of knowledge of nurses administering chemotherapy sufficient?	13.6
Service Delivery and Organisation of Care	What is the effect of staffing levels & skill mix on outcomes of care?	21.4
	Are staff shortages detrimental to practical/emotional support	9.7
	What impact do different chemotherapy regimes have on nurse workload?	9.7
Effects of Role on Nurses' Health and Support Needs	Psychological effects on health care professionals working in BMT/ haematology	21.4
	What are the psychological support needs of nurses & other health care professionals?	20.4
	Is effective clinical supervision available to nurses in haemato-oncology?	17.5
Communication/ Patient Information and Education	Effect of communication good/bad on patients	18.4
	Patients' & relatives' views on the information and support they receive regarding diagnosis and treatments	17.5
	Education and pre-assessment of patients having chemotherapy	13.6
Ethical Decision Making	When to actively treat and when to withdraw treatment	19.4
	Making decision when active treatment ends and palliative treatment begins	17.5
	How can end of journey decision making with patients be improved?	15.5
Utilising Knowledge and Developing the Evidence Base for Practice	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	14.6
	What is best practice in protective isolation care? Is there a best practice?	14.6
	Develop evidence base of optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	9.7
	Clear guidelines on mucositis management	9.7
Nursing Interventions and Care	How can prevention of infection measures be improved?	16.5
	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	12.6
	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	12.6
Symptom Management	Disease & treatment related fatigue	26.2
	How can the side-effects of chemotherapy be reduced?	18.4
	Management of GVHD treatment complications	16.5
Psychosocial Wellbeing and Support	What are the psychosocial support needs of patients with haematological cancers & their families?	12.6
	Should a psychologist/ counsellor be involved at ward level for patients and relatives?	11.7
	Are sexuality issues addressed?	8.7
Patient and Family Experience	What do patients expect/require from nurses	12.6
	Psychological effects of relapse for the patient & family	8.7
	Effect of low staff morale and staffing on experiences of isolated patient	7.8
Nurses' Role	How effective is the CNS role in haemato-oncology?	15.5
	Critical care skills are they an essential requirement for haematology/BMT nurses?	13.6
	Minimum skills/requirements for UK haematology nurses researchers/ managers	13.6

Table 13: Comparison of Most Highly Rated Third Priorities in Each Category to Second Round Results

Category	**Topic**	**Score Round 3 (%)**	**Rank in Category Round 2**
Effects of Role on Nurses' Health and Support Needs	Availability of training and support and effects on stress development	25.2	8 (last)
Symptom Management	Disease and treatment related fatigue	21.4	2
Ethical Decision Making	How can end of journey decision making with patients be improved?	17.5	5
Education	What is nurses' knowledge of neutropenic sepsis?	14.6	1
Communication/Patient Information and Education	Timeliness/quality/amount of information at diagnosis and relapse	14.6	4
Nurses' Role	Career development for haemato-oncology nurses	14.6	6
Nursing Interventions and Care	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	14.6	3
Utilising Knowledge and Developing the Evidence Base for Practice	Oral care protocol – what's best?	11.7	5
	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	11.7	3
Patient and Family Experience	How important to patients is access to a CNS?	11.7	6
Psychosocial Wellbeing and Support	How could nurses improve support for patients?	10.7	2
Service Delivery & Organisation of Care	Are staff shortages detrimental to practical/emotional support?	9.7	1

Table 14: Top 3 Third Priority Topics by Category

Category	Top 3 third priorities	%
Education	What is nurses' knowledge of neutropenic sepsis?	14.6
	How can chemotherapy training & administration be standardised throughout the UK?	9.7
	Is depth of knowledge of nurses administering chemotherapy sufficient?	8.7
	How can high standards/levels of knowledge in cytotoxic administration be maintained?	8.7
	Educational needs of nurses at 3 levels novice, developing practice, expert	8.7
Service delivery and Organisation of Care	Are staff shortages detrimental to practical/emotional support?	9.7
	What is the effect of staffing levels & skill mix on outcomes of care?	8. 7
	What impact do different chemotherapy regimes have on nurse workload?	6.8
Effects of Role on Nurses' Health and Support Needs	Availability of training and support and effects on stress development	25.2
	What are the psychological support needs of nurses & other health care professionals?	17.5
	Psychological effects on health care professionals working in BMT/ haematology	11.7
Communication/ Patient Information and Education	Timeliness/quality/amount of information at diagnosis and relapse	14.6
	Effect of communication good/bad on patients	13.6
	Education & pre-assessment of patients having chemotherapy	10.7
	What information do patients require on specific aspects of care?	10.7
Ethical Decision Making	How can end of journey decision making with patients be improved?	17.5
	Does the patient receive sufficient information to provide informed consent?	14.6
	What is the nurses' advocacy role for haemato-oncology patients?	12.6
Utilising Knowledge and Developing the Evidence Base for Practice	Oral care protocol – what's best?	11.7
	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	11.7
	What is best practice in protective isolation care? Is there a best practice?	8.7
	Treatment safety including blood	8.7
Nursing Interventions and Care	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	14.6
	What is the role of alternative therapies?	10.7
	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	9.7
Symptom Management	Disease & treatment related fatigue	21.4
	Is pain control during bone marrow biopsies effective?	17.5
	Management of GVHD treatment complications	16.5
Psychosocial Wellbeing and Support	How could nurses improve support for patients?	10.7
	What are the psychosocial support needs of patients with haematological cancers & their families?	9.7
	Should a psychologist/counsellor be involved at ward level for patients and relatives?	8.7
	Psychological effects of haematological cancers	8.7
Patient and Family Experience	How important to patients is access to a CNS?	11.7
	Patient experiences of symptom control	6.8
	What effect does a palliative prognosis have on the patient?	6.8
	Support of carers	6.8
Nurses' Role	Career development for haemato-oncology nurses	14.6
	How effective/successful are nurse-led services?	12.6
	Minimum skills/requirements for UK haematology nurses/researchers/ managers	12.6
	Development of extended role for nurses in haemato-oncology	12.6

Overall Priorities

Comparison of topics most highly rated as first, second and third priorities demonstrated considerable overlap. In 7 categories, 12 topics appear in all 3 priority areas (Table 15).

Table 15: Topics Appearing as First, Second and Third Priorities

Category	**Topic**
Education	How can chemotherapy training and administration be standardised throughout the UK?
	Is depth of knowledge of nurses administering chemotherapy sufficient?
Service Delivery and Organisation of Care	What is the effect of staffing levels and skill mix on outcomes of care?
	Are staff shortages detrimental to practical/emotional support?
Effects of Role on Nurses' Health and Support Needs	What are the psychological support needs of nurses and other health care professionals?
Communication/ Patient Information and Education	Effect of communication good/bad on patients
Utilising Knowledge and Developing the Evidence base for Practice	What is best practice in protective isolation care? Is there a best practice?
	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing
Nursing Interventions and Care	Are antimicrobial diets/clean food regimes beneficial in neutropenia?
	Disease and treatment related fatigue
	Management of GVHD treatment complications
Psychosocial Wellbeing and Support	What are the psychosocial support needs of patients with haematological cancers and their families?

In all categories a number of topics appear twice as either first and second priorities, first and third priorities or second and third priorities (Appendix 13). This overlap between first, second and third priorities adds credibility to the importance of topics as research priorities. To determine the importance of individual topics an overall score was calculated by adding the first, second and third priority scores (Table 16).

Table 16: Three Most Commonly Selected Topics by Category

Category	Statement	Priority 1 (%)	Priority 2 (%)	Priority 3 (%)	Total (%)
Education	What is nurses' knowledge of neutropenic sepsis?	28	12	15	55
	How can chemotherapy training & administration be standardised throughout the UK?	20	18	10	48
	Is depth of knowledge of nurses administering chemotherapy sufficient?	10	14	9	33
Service Delivery and Organisation of Care	What is the effect of staffing levels & skill mix on outcomes of care?	17	21	9	47
	Are staff shortages detrimental to practical/emotional support?	17	10	10	37
	Transition from curative to palliative care and treatment	15	5	7	27
Effects of Role on Nurses' Health and Support Needs	Long term health risks of nurses exposed to chemotherapy/antibiotics	45	14	9	69
	What are the psychological support needs of nurses & other health care professionals?	15	20	18	53
	Psychological effects on health care professionals working in BMT/haematology	12	21	12	45
Communication/Patient Information and education	Patients' & relatives' views on the information & support they receive regarding diagnosis & treatments.	47	18	8	73
	Effect of communication good/bad on patients	12	18	14	44
	Timeliness/quality/amount of information at diagnosis and relapse	7	8	15	30
Ethical Decision Making	Making decision when active treatment ends & palliative treatment begins	32	18	11	61
	When to actively treat and when to withdraw treatment	21	19	9	49
	Does the patient receive sufficient information to provide informed consent?	18	14	15	47
Utilising Knowledge and Developing the Evidence Base for Practice.	What is best practice in protective isolation care? Is there a best practice?	27	15	9	51
	National guidelines/standards of care for central venous catheters including dressings, cleaning & flushing	21	15	12	48
	Clear guidelines on mucositis management	12	10	9	31
Nursing Interventions and Care	Management & care of neutropenic patients	47	12	6	65
	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	10	13	15	38
	How can prevention of infection measures be improved?	10	17	9	36
Symptom Management	How can the side-effects of chemotherapy be reduced?	51	18	9	78
	Disease and treatment related fatigue	18	26	21	65
	Management of GVHD complications	9	17	17	43

Table 16 cont: Three Most Commonly Selected Topics by Category

Category	Statement	Priority 1 (%)	Priority 2 (%)	Priority 3 (%)	Total (%)
Psychosocial wellbeing & support	Quality of life – What does it really mean to the patient?	32	7	5	44
	What are the psychological support needs of patients with haematological cancers & their families?	13	13	10	36
	How could nurses improve support for patients?	9	5	11	25
	Should a psychologist/counsellor be involved at ward level for patients & relatives?	4	12	9	25
Patient & family experience	What do patients expect/require from nurses?	28	13	4	45
	How important to patients is access to a CNS?	9	5	12	26
	Effect of low staff morale & staffing on experiences of isolated patient	8	8	5	21
	Psychological effects of relapse for the patient & family	7	9	5	21
Nurses' role	How effective/successful are nurse-led services?	29	13	13	55
	Critical care skills are they an essential requirement for haematology/BMT nurses?	18	14	5	37
	Minimum skills/requirements for UK haematology nurses/researchers/managers	7	14	13	34

Comparison of Most Highly Rated Topics per Category Rounds 2 and 3

Comparison of the overall scores for the 3 most highly rated priorities in each category in rounds 2 and 3 demonstrated considerable agreement (Table 17). It was not possible to determine agreement between the 2 rounds statistically because of the different methods used to prioritise topics in rounds 2 and 3. Consistency of responses was therefore explored. Responses were judged to be consistent if topics appeared in the top 3 priorities in both rounds. Topics identified in the top 3 priorities in round 3 only but reaching consensus in round 2 were also considered to be consistently rated as priorities. Topics rated in the first 3 priorities in round 2 but not included in the first 3 priorities in round 3 were excluded because in the latter round the overall score attributed to topics other than the top 3 tended to be low.

Consistency between first priorities was easily identified as these were the same in both rounds and in all categories except 'utilising knowledge and developing the evidence base for practice'. Yet, although not ranked in exactly the same order all 3 of the highest rated topics in this category and 5 other categories were the same in both rounds. In a further 3 categories (ethical decision making, symptom management and nurses' role) the first 3 priorities were ranked in the same order in both rounds (a full list of ranks for rounds 2 and 3 can be found in Appendix 14).

Less consistency was immediately apparent for a minority of topics. In the 'patient and family experience' category the topic ranked second in round 3 'how important to patients is access to a CNS?' was ranked sixth in the category in round 2. This topic did, however, reach the predetermined level of consensus in round 2 implying consistent identification of this topic as a priority in both rounds.

Comparison of results of the 2 rounds for the remaining 4 categories also demonstrated less consistency. In the education category the topic ranked second in round 2 'access to haematological nurse education/courses' was ranked fifth in round 3 receiving a low overall score. The topic ranked third in round 3 'is depth of knowledge of nurses administering chemotherapy sufficient?' was ranked seventh in category in round 2 and did not reach the predetermined level of consensus. These topics were therefore excluded from the final list of priorities as they were not rated highly in both rounds.

Table 17: Comparison of 3 Most Highly Rated Topics by Category Rounds 2 & 3

Category	**Statement**	**Rank in category Round 2**	**Rank in category Round 3**
Education	What is nurses' knowledge of neutropenic sepsis?	1	1
	Access to haematological nurse education/courses	2	5
	How can chemotherapy training & administration be standardised throughout the UK?	3	2
	Is depth of knowledge of nurses administering chemotherapy sufficient?	7	3
Service Delivery and Organisation of Care	Are staff shortages detrimental to practical/emotional support?	1	2
	What is the effect of staffing levels & skill mix on outcomes of care?	2	1
	Transition from curative to palliative care and treatment	3	3
Effects of Role on Nurses' Health and Support Needs	Long term health risks of nurses exposed to chemotherapy/antibiotics	1	1
	Psychological effects on health care professionals working in BMT/haematology.	2	3
	What are the psychological support needs of nurses & other health care professionals?	3	2
Communication /Patient Information and Education	Patients' & relatives' views on the information & support they receive regarding diagnosis & treatments	1	1
	Provision of information for children of adults with a haematological disorder	2	9
	Effect of communication good/bad on patients	2	2
	Timeliness/quality/amount of information at diagnosis and relapse	4	3
Ethical Decision Making	Making decision when active treatment ends & palliative treatment begins	1	1
	When to actively treat and when to withdraw treatment	2	2
	Does the patient receive sufficient information to provide informed consent?	3	3
Utilising Knowledge and Developing the Evidence Base for Practice	Clear guidelines on mucositis management.	1	3
	What is best practice in protective isolation care? Is there a best practice?	1	1
	National guidelines/standards of care for central venous catheters including dressings, cleaning & flushing	3	2
Nursing Interventions and Care	Management & care of neutropenic patients	1	1
	How can prevention of infection measures be improved?	2	3
	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	3	2
	Nutritional support for patients undergoing transplant procedures & high dose chemotherapy	3	5
Symptom Management	How can the side-effects of chemotherapy be reduced?	1	1
	Disease and treatment related fatigue	2	2
	Management of GVHD complications	3	3
Psychosocial Wellbeing and Support	Quality of life – What does it really mean to the patient?	1	1
	How could nurses improve support for patients?	2	3
	What are the psychological support needs of patients with haematological cancers & their families?	3	2
Patient and Family Experience	What do patients expect/require from nurses?	1	1
	Psychological effects of relapse on the patient & family	2	3
	Effect of low staff morale & staffing on experiences of isolated patient	3	3
	How important to patients is access to a CNS?	6	2
Nurses' Role	How effective/successful are nurse-led services?	1	1
	Critical care skills are they an essential requirement for haematology/BMT nurses?	2	2
	Minimum skills/requirements for UK haematology nurses/researchers/managers	3	3

In the communication/patient information and education category the topic 'timeliness/quality/amount of information at diagnosis and relapse' ranked third in round 3 and fourth in round 2. This topic did, however reach the predetermined level of consensus in round 2 indicating agreement between rounds and was therefore included in the overall list of priorities. The topic ranked third in round 2 'provision of information for children of adults with a haematological disorder' ranked ninth in the category in round 3 receiving an overall score of only 16% and was therefore excluded from the final list of priorities.

Similarly in the category 'nursing interventions and care', 2 topics tied for third place in round 2. One of these topics 'nutritional support for patients undergoing transplant procedures and high dose chemotherapy' was ranked fifth in round 3 and not regarded as a consistent response.

In 2 categories, topics included in the first 3 priorities in round 3 failed to reach the level of consensus in round 2: 'what are the psychological support needs of nurses and other health care professionals?', 'psychological effects on health care professionals working in BMT/haematology (effects of role on nurses' health and support needs category), and 'management of GvHD complications' (symptom management category). Yet, in both these categories the same 3 topics were the most highly rated in both rounds indicating agreement on their importance as research priorities.

Between the 2 rounds and across all 11 categories agreement was reached on all but 4 of the highest rated priorities. These 4 topics have already been identified and are highlighted in Table 17. The 33 remaining topics were the most consistently highly rated in both rounds. Several of the topics are broad and a number of research questions could be developed from these topics, for example 'how can the side-effects of chemotherapy be reduced?' Several other topics relate to the need for guidance on best practice for example 'clear guidelines on mucositis management' reflecting the need for systematic reviews of the literature and development and dissemination of guidelines for practice. The 33 topics do, however, represent a varied and useful foundation for further exploration, discussion and development of coordinated programmes of future research.

Conclusion

Results demonstrated remarkable consistency between rounds 2 and 3 and potentially provide a strong foundation for future research and advancing knowledge for haemato-oncology nursing practice. The poor response rate in round one was, however, disappointing and the potential for biasing results has to be acknowledged. This poor response rate was not entirely unexpected and it was anticipated that those who responded to round one and self-nominated would be interested in the research and likely to stay involved. The high response rates in rounds 2 and 3 support this assumption. An anomaly does, however, exist in that some participants responded to rounds 1 and 3 only. Reasons for this are unclear and could be suggestive of questionnaire fatigue but this does not appear to be the full explanation as these individuals took time to respond to round 3 implying their interest in the research was maintained. The number of new respondents in round 3 also adds credibility to the request to photocopy the questionnaire to encourage colleagues to respond as a means of increasing response rates.

The high numbers of respondents working in either dedicated haemato-oncology units or areas where haemato-oncology was combined with another speciality adds to the credibility of results. The attributes of respondents further enhance the credibility of results with large numbers working directly with patients and exposed on a daily basis to their needs and problems. Furthermore, most respondents had worked in the speciality for long periods of time and held relevant post-registration qualifications confirming their status as individuals with the requisite knowledge and experience to identify relevant research priorities. The spread of respondents across different areas of haemato-oncology is also perceived to be valuable in the identification of research priorities across the full spectrum of haemato-oncology nursing.

The large number of research priorities identified in round 1 highlighted the vast amount of data that may be obtained in a Delphi study. It also indicates the diverse range of topics that practising nurses perceive to require research. The iterative nature of a Delphi study is emphasised throughout the chapter with the decision trail clearly indicated to enhance the reliability and validity of results. Involvement of the expert panel proved invaluable in the categorisation and reduction of the vast amount of data received in response to round 1 and subsequent questionnaire design.

Results from round 2 demonstrated close clustering of responses and lack of discrimination between topics precluding conclusions being drawn about research priorities and influencing the decision to undertake a third round. In deciding to undertake a third round decisions had to be made in light of round 2 results particularly in relation to increasing discrimination between topics. Again involvement of the expert panel was invaluable in designing the questionnaire for round 3 and determining the way forward.

Results from round 3 demonstrated much clearer discrimination between topics. Furthermore, topics identified as high priority demonstrated remarkable consistency to priority topics in round 2. This consistency between rounds demonstrates stability of results between rounds thereby increasing the credibility of results and confirming the importance of these topics as research priorities. The significance of these results does, however, require further interpretation and discussion before they can be disseminated, used as a foundation for developing new knowledge and advancing knowledge for haemato-oncology nursing practice or translated into programmes of research. Results require to be discussed in relation to the limitations of the study and the results of previous relevant research. Exploration and discussion of these issues therefore forms the basis of the subsequent chapter.

CHAPTER 7: DISCUSSION

Introduction

No previous studies have examined research priorities for the spectrum of haemato-oncology nursing. This study has therefore generated new knowledge in identifying topics practising nurses perceive to be priorities for future research. As no previous studies focus on this speciality results are discussed in relation to previous HSCT and cancer nursing studies. All research studies do, however, have methodological limitations that affect results. The significance of results and the limitations of the study are therefore also discussed.

Research Priorities

The 10 most commonly selected research priorities identified in this study show both similarities and differences to priorities identified previously in HSCT and cancer nursing studies (Tables 18 and 19). Clearly identifiable research themes that emerged from this study encompassed: chemotherapy, psychosocial issues and information giving, psychological support needs of nurses, ethical considerations, nurse-led services and guidelines.

Table 18: Comparison of Most Commonly Selected Topics with Previous HSCT Priorities

Oncology Nursing Society BMT Special Interest Group 1991	Molassiotis 1997a	Current study
Coping strategies of BMT nurses	Infection control and isolation techniques	How can the side-effects of chemotherapy be reduced?
Critical care issues of BMT	Psychosocial issues	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments
Survivorship issues	Pain management	Long term health risks of nurses exposed to chemotherapy/antibiotics
Comparison of isolation techniques	Management of nausea and vomiting	Management and care of neutropenic patients
Psychosocial issues of BMT population	Fertility issues	Disease & treatment related fatigue
Autologous BMT issues	Quality of life (short- and long-term)	Making decision when active treatment ends and palliative treatment begins
Ethical decision making	Central line catheter care	What is nurses' knowledge of neutropenic sepsis?
Management of mucositis	Total parenteral nutrition	How effective/successful are nurse-led services?
Quality of life in BMT population	Impact of BMT on family/spouses	What are the psychological support needs of nurses & other health care professionals?
Nursing knowledge of immunology during BMT	Primary care nursing systems	What is best practice in protective isolation care? Is there a best practice?

Table 19: Research Priorities Identified in Selected Cancer Nursing Studies

Rank	Browne et al, 2002	McIlfatrick & Keeney, 2003	Yates et al, 2002	Berger et al, 2005	Ropka et al, 2002	Rustøen & Schjølberg, 2000	Murphy & Cowman, 2006	Cohen et al, 2004	Barrett et al, 2001
1	Communication, information giving & educational needs	Identification of communication issues for patients throughout the cancer journey	Psychological support	Quality of life	Pain	Quality of life	Effectiveness of nurse-led clinics on oncology services	Acute and chronic pain	What strategies would be most helpful in allowing nurses time to provide emotional support to cancer patients and carers?
2	Cancer nursing research	Exploring the levels of stress and burnout for cancer nurses	Pain management	Participation in decision making about treatment in advanced disease	Quality of life	Psychosocial support/ counselling	Levels of stress & burnout for cancer nurses	Infection rates and control	What are the barriers to "changing lanes" from active treatment to palliative care?
3	Psychological experiences and care	Continuity of care between hospital, community and hospice settings	Symptom management	Patient/family education	Early detection of cancer	Patient participation in decision making	Identification of communication issues for patients throughout their cancer journey	Job satisfaction	What are the barriers to facilitating death with dignity for the dying cancer patient?
4	Experiences of disease and its treatment	The experience of a single parent diagnosed with cancer	Health system issues	Participation in decision making about treatment	Prevention/ risk reduction	Communication patient-nurse	Continuity of care among hospital, community and hospice settings	Nurse-patient ratios & staffing	What is the most effective way to involve the cancer patient in care decisions?
5	Cancer nursing & symptom intervention/ control	Information needs of patients post treatment	Patient/community education	Pain	Neutropenia/ immuno-suppression	Nurse burnout & self-care	Development of nurse-led interventions for the management of pain	Improving retention of nurses and reducing turnover	What approaches should be used to involve the caregivers in the care of the cancer patient?

Table 19 continued: Research Priorities Identified in Selected Cancer Nursing Studies

Rank	Browne et al, 2002	McIlfatrick & Keeney, 2003	Yates et al, 2002	Berger et al, 2005	Ropka et al, 2002	Rustøen & Schjølberg, 2000	Murphy & Cowman, 2006	Cohen et al, 2004	Barrett et al, 2001
6	Cancer nursing education	Patients' perceptions of their pain management	Management/ organisational issues	Tobacco use and exposure	Hospice/end of life care	Ethics	Availability of services to support patients & carers in the community	Salary inequities over time	Does a positive mental outlook affect the cancer patient's attitude to his or her prognosis?
7	Stress burnout & coping in cancer nursing	Development of nurse led interventions for the management of pain	Medical/treatment issues	Screening/ early detection of cancer	Oncological emergencies	Continuation/ termination of active treatment	The effectiveness of communication between professionals on discharge.	Nausea, vomiting and antiemetic regimes	How effective is a patient education program related to cancer pain management?
8	Evaluating cancer nursing interventions	Effectiveness of communication between professionals on discharge	Ethics and end of life issues	Prevention of cancer/cancer risk reduction	Suffering	Cancer rehabilitation	Role of the nurse in "breaking bad news"	Drug toxicities	What are the educational needs of cancer patients receiving chemotherapy?
9	Protocols, standards, guidelines & criteria	Effects of a cancer diagnosis on the spouse	Health team issues	Palliative care	Fatigue	Recurrence of primary cancer	Educational needs of cancer nurses	Patient understanding of options at end of life	What are the effects of lack of disclosure about the prognosis on cancer patients and caregivers?
10	Identification of problems in providing palliative care in the acute setting	Patient education methods/ Processes	Complementary therapies	Evidence based practice	Ethical issues	Coping/stress management	Experience of sexuality and the cancer experience on patient & family	Stress management for nurses	What strategies do nurses employ to cope with difficult family situations of cancer patients?

Chemotherapy

The first major theme focuses on chemotherapy highlighting both the side-effects experienced by patients and the potential long-term health risks of nurses exposed to these agents. Six of the most commonly selected topics relate to this theme with the most commonly selected topic being 'how can the side-effects of chemotherapy be reduced?' The side-effects of chemotherapy are, however, many and varied and a number of research questions could be devised from this one question. Further exploration of this topic would be required to determine the priority areas for future research. Specific side-effects of neutropenia and fatigue were, however, also identified.

Neutropenia

Neutropenia is a life-threatening complication of haematological cancers and their treatment and its importance in care is reflected in the fourth, seventh and tenth most commonly selected priorities; 'Management and care of neutropenic patients','What is nurses' knowledge of neutropenic sepsis?' and 'What is best practice in protective isolation care? Is there a best practice?' Infection control and isolation practices were also ranked first in the Molassiotis' (1997a) study and several cancer nursing studies rank neutropenia and protective isolation practices in the top 10 priorities (Stetz et al, 1995, Daniels & Ascough, 1999; Ropka et al, 2002). People with haematological cancers are more likely to experience lower neutrophil counts for a longer period of time than those with solid tumours (Hart, 2006) and it is not surprising that these issues were regarded as high priority for haemato-oncology nurses.

Protective isolation practices vary, ranging from very strict, purpose built units incorporating positive pressure air filtration systems and use of strict aseptic technique to commonsense measures such as handwashing and avoiding those with obvious infections. Existing research exploring the effectiveness of protective isolation is inconclusive although some support exists for the use of positive pressure air filtration systems to reduce fungal infections such as aspergillus (Hahn et al, 2002; Mank & van der Lelie, 2003; Larson & Nirenberg, 2004).

Ethical considerations and the potential for increasing the occurrence of life-threatening infections impede the conduct of research determining the effectiveness of protective isolation practices. The need for coordinated multi-centre research to establish effective protective isolation practices and the need for national guidelines has previously been highlighted (Hart, 2006). Leadership and action are, however, required to progress this agenda.

Fatigue

Management of fatigue tied as the fourth most commonly selected priority. Fatigue is increasingly recognised as a common experience for people with cancer. Severity of fatigue is, however, greater for individuals with haematological cancers, often present at diagnosis, and perceived by patients to be poorly addressed by health care professionals (Cleeland & Wang, 1999; Curt et al, 2000; Stone et al, 2000; Wang et al, 2002). This topic area has not featured in either of the previous HSCT priority studies and has only been identified as a priority in two cancer nursing studies (Ropka et al, 2002; Lee et al, 2003). A small number of studies investigating interventions to reduce fatigue were identified in the literature review (Coleman et al, 2003; So & Tai, 2005; Kim & Kim 2005a) but further research into effective interventions is required.

The need to identify effective interventions for several other side-effects was also highlighted in the 33 most commonly selected side-effects including guidelines on mucositis management, the benefits of antimicrobial diets, nutritional support for HSCT and high dose chemotherapy, and managing the complications of graft versus host disease. This further emphasises the need for further research demonstrating the effectiveness of nursing interventions (Richardson et al, 2002).

Health Risks of Cytotoxic Drugs

Concern over the health risks of cytotoxic drugs for health care professionals was the third most commonly selected topic. Various other aspects of chemotherapy training were included in the 33 highest rated topics and focus on education and standardisation of practice. Chemotherapy was not identified as a priority by either ONS (1991) or Molassiotis (1997a). Health issues associated with handling cytotoxic drugs have, however, been persistently prioritised in cancer nursing studies since 1978. The only study to rank this priority so highly in the past is that of Daniels & Ascough (1999) and it was rated as one of the lowest priorities in the Browne et al (2002) study.

The continued appearance of this topic as a research priority may be influenced by the difficulties in determining the level of health risk these drugs pose to health care professionals. Cytotoxic drugs are potentially hazardous to health care professionals as they are teratogenic, mutagenic and carcinogenic (Allwood et al, 2001). A precise level of risk is difficult to quantify as studies are rather dated and have methodological limitations such as small sample sizes, extraneous variables affecting results, difficulties in quantifying type and length of exposure (Falck et al, 1979; Caudell et al, 1988; Cloak et al, 1985).

It has been suggested that risk to health care professionals may have decreased since these studies were undertaken due to changes in the preparation of cytotoxic drugs in ward environments with little personal protective equipment to central preparation of drugs in specialised areas in pharmacy departments and more standardised use of personal protective equipment (Dranitsaris et al, 2005). Recent environmental contamination studies have, however, demonstrated considerable levels of contamination despite these precautions (Connor et al, 1999; Ziegler et al, 2002). Furthermore, the external surfaces of intact vials containing cytotoxic drugs have been found to be contaminated when delivered from the manufacturers and some gloves and gowns used as personal protective equipment may allow penetration of drugs (Connor et al, 1999; Harrison & Kloos, 1999; Favier et al, 2003). Following recommended safe handling procedures may therefore not provide complete protection for health care workers.

The need for coordinated large scale multi-disciplinary research to determine the effectiveness of safe handling practices and the impact of education and training has previously been highlighted (RCN, 1998; Grundy, 1998; Allwood et al, 2001). To date, little progress appears to have been made although the importance of addressing the risk of exposure has been recently emphasised (Sewell, 2007). Sewell suggests that personal exposure testing is limited due to extraneous variables that may affect results for example smoking and other lifestyle factors and advocates local monitoring of environmental contamination and the effectiveness of protective measures used. National coordination of such environmental monitoring would, however, provide much more robust evidence. The persistent occurrence of the health risks posed by cytotoxic drugs as a research priority clearly demonstrates the concern of nurses involved in their administration. Health and safety issues for health care professionals are highlighted and the need for high level national leadership to progress the research agenda appears to be crucial.

Psychosocial Issues and Information Giving

Psychosocial issues and information giving formed a further major theme with the second most commonly selected topic focusing on patients' opinions of their psychological care at specific points in their illness and a further 8 of the 33 overall priorities focusing on other psychosocial issues. Psychosocial issues were also identified by both the ONS (1991) and Molassiotis (1997a) although not as highly rated. Aspects of information giving, communication and psychosocial support have, however, been rated highly in other studies (Bakker & Fitch, 1998; Rustøen & Schjølberg, 2000; Browne et al, 2002; McIlfatrick & Keeney, 2003; Murphy & Cowman, 2006).

McIlfatrick & Keeney (2003) suggest that these topics may have been prioritised so highly because of the significance of the psychosocial aspects of cancer care. It may also indicate that psychosocial aspects of care, communication and information giving are not perceived to be well-addressed by practising nurses. The paucity of research focusing on the psychosocial aspects of haematological cancers and patient experiences identified in the literature review (McGrath, 2000) is also likely to have contributed to prioritisation of these aspects of care.

The importance of communication and information giving is undisputed with communication being regarded as a vital component of cancer care (Booth et al, 1999; Wilkinson et al, 2003). Despite the importance of these issues studies report deficits in the communication abilities of cancer nurses (Wilkinson, 1991; Kruijver et al, 2000). Furthermore, communication skills courses do not always result in sustained behaviour change although some success has been demonstrated with particular programmes (Wilkinson et al, 1999; Kruijver et al, 2001; Wilkinson et al, 2003). Further research evaluating the effectiveness of differing methods of developing and maintaining psychological support, communication and information giving skills would be valuable in addressing these issues.

One difference between this study and previous studies appears to be the emphasis on the effects of health policy and socio-political context on psychosocial care. The emphasis on patients' views reflects the paucity of research in this area and political and professional commitment to obtaining patients' and relatives' opinions and experiences to inform care and research agendas (SEHD, 2004; DH, 2005; Wright et al, 2006). Other priority topics reflect concern about health care policy and the effects of staff shortages and skill mix on psychosocial care and patient outcomes. Research exploring these issues is vital in ensuring quality of care and patient safety. This theme is also closely connected to the psychological support needs of nurses which was also included in the 10 most commonly selected topics in this study.

Psychological Support Needs of Nurses

The psychological support needs of nurses and other health care professionals were not identified in previous HSCT studies but feature in previous cancer nursing studies (Rustøen & Schjølberg, 2000; Cohen et al, 2004). Various issues may impact on the psychological support needs of health care professionals working in haemato-oncology including difficulties with recruitment and retention of NHS staff, staff shortages and the intense nature of relationships with patients in haemato-oncology settings. Scarce resources and heavy workloads also lead to difficulties in meeting the emotional demands of patients (DH, 2000b; Molassiotis & Haberman, 1996; Kelly et al, 2000; McGrath, 2000; McGrath et al, 2003; Jackson, 2006).

Nursing stress appeared in all 3 reviews of haemato-oncology nursing research examined in the literature review but little recent research appears to have been undertaken. Furthermore, existing research is focused on HSCT environments rather than haemato-oncology settings generally. Current nursing shortages make recruitment and retention of nurses in all specialities crucial and support for the workforce appears to be central to this (Molassiotis & Haberman, 1996). This issue is not unique to haemato-oncology nursing but effects may be compounded by the intense relationships formed with patients and their relatives (Molassiotis & Haberman, 1996; Kelly et al, 2000; McGrath, 2000). Research investigating these issues is therefore vital to the health, wellbeing and retention of the multi-professional workforce.

Ethical Considerations

Ethical considerations and palliative care were sixth in the top 10 most commonly selected priorities and also included in the 33 overall priorities. Ethical decision making was included in the ONS (1991) priorities but not in the Molassiotis (1997a) study. Palliative care was not rated as a priority by either the ONS (1991) or Molassiotis (1997a). The same issues of ethical decision making in the transition from active treatment to palliative care were, however, included in some of the cancer nursing studies (Rustøen & Schjølberg 2000; Barrett et al, 2001; Yates et al, 2002).

The identification of these priority areas may be reflective of a growing recognition of the importance of palliative care in haemato-oncology and the difficulties experienced by practitioners in relation to clinical decision making. Palliative care has generally not been well addressed in haemato-oncology (McGrath, 2001a & b; McGrath, 2002a & b; McGrath & Holewa, 2006; 2007). Reasons for this include the potentially curable nature of many haematological cancers and the associated highly technical treatment involved (McGrath, 2001a & b). In haematological cancers there is often a rapid transition from curative to palliative and terminal care and patients, their relatives and the health care professionals caring for them may experience difficulties in adapting to the rapid change in circumstances. Difficulties may also be experienced in applying palliative and supportive care principles in acute and high technology areas such as haemato-oncology (McGrath, 2002b). Furthermore, Barrett et al (2001) suggest there is little to help practitioners manage end of life issues in their everyday practice despite the wealth of literature on the subject and indicate that research is required to determine how these issues can be best addressed. Addressing these issues would also support the implementation of research into practice.

Nurse-led Services

The effectiveness of nurse-led care/services does not appear as a priority in the previous HSCT studies and appears to reflect changes in contemporary health care delivery and nursing roles/skill mix. Several other topics within the 33 overall priorities also reflect this theme and these findings are consistent with those of McIlfatrick & Keeney (2003) and Murphy & Cowman (2006). The latter study was based on the research priorities identified in the former study so a degree of similarity in the results of the two studies would be expected.

Identification of these research priorities is not, however, new. The need to evaluate nurse-led care, the effects of staff ratios/skill mix on patient outcomes psychosocial support, patient and carer issues and ethical decision making were all identified as themes for future research a decade ago in the USA (Haberman, 1997). Yet, to date this research agenda has not been progressed. Such research is now crucial and urgently required to ascertain the efficiency and effectiveness of the dynamic and changing roles of nurses and their effectiveness and efficacy on patient care and provide essential information for future professional and service development.

Guidelines

Several of the topics identified in the 33 overall priorities were consistent with priorities identified in the previous HSCT studies and cancer nursing studies. The consistency of topics arising as research priorities has previously raised questions about progress made with research and the success of disseminating and implementing research findings into practice (Degner et al, 1987). Several Delphi studies have reported responses that demonstrated a lack of awareness of previous research or relevant literature (Daniels & Ascough, 1999; Soanes et al, 2000; Daniels & Howlett, 2001). On probing, however, Hagen & Hunt (1998) found that different aspects of the topic that had not previously been researched were being identified.

In this study, several of the topics identified as priorities (e.g. protective isolation. mucositis management, central line catheter care) suggest that haemato-oncology nurses want guidance on best practice perhaps reflecting the incompleteness of the evidence base in these areas rather than a lack of awareness of existing research. Further work is, however, required to ascertain the particular issues that continue to cause concern in practice. The need for large, well-designed and conducted trials in some of these areas has also already been identified (Rubenstein et al, 2004; Sonis et al, 2004; Worthington et al, 2006; Hart, 2006). Systematic reviews, development of guidelines and best practice statements may all help to increase the dissemination and implementation of research findings into practice.

The results of this study suggest that research priorities in haemato-oncology nursing have similarities and differences to research priorities previously identified in both HSCT and cancer nursing. Differences do, however, exist in the research methods used in different studies and should be considered in interpreting results. Both the ONS (1991) and Molassiotis (1997a) used survey methodology as did some cancer nursing studies (e.g. Ropka et al, 2002; Berger et al, 2005). Others conducted Delphi studies (e.g. Browne et al, 2002; McIlfatrick & Keeney, 2003; Cohen et al, 2004). Studies were also conducted in different countries and may also have affected the priorities identified. Despite these differences common themes can be identified and suggest some consistency in relation to establishing research priorities.

Some of the priorities identified in this study for example the health risks associated with cytotoxic drugs, and communication and information giving are not unique to haemato-oncology nursing but applicable across the spectrum of cancer nursing. In considering effective use of scarce resources for research it would be more efficient to collaborate with others conducting research on these topics and focus on aspects of care specific to haemato-oncology nursing. The differences between this study and previous studies appear to reflect contemporary practice and provide direction for future research. In interpreting results limitations of the study do, however, require to be considered.

Limitations of the Study

Response Rates

The response rate to the first questionnaire was poor (17%) but this is not unusual. Response rates to surveys mailed to the general public are noted to be between 10% and 20% (Funkhouser & Grant, 1989) while response rates to Delphi studies undertaken by nursing organisations between 1985 and 1995 varied between 15% and 80% (Rudy, 1996). Other studies have demonstrated response rates ranging from 16% to 79% in round 1 (Bond & Bond, 1982; Degner et al, 1987; Daniels & Ascough, 1999; Soanes et al, 2000; Barrett et al, 2001; Browne et al, 2002; Kirkwood et al, 2003; McIlfatrick & Keeney, 2003).

Response rates to rounds 2 and 3 were, however, good at 72% and 70% respectively. Response rates in subsequent rounds are noted to decline in most Delphi studies and the potential for decreasing response rates increases with each round (McKenna 1994; Keeney et al, 2001). The attrition rate from round 1 to round 2 in this study was, however, extremely small compared to attrition rates from the second round of other Delphi studies which range from 9% to 72% (Bond & Bond, 1982; Degner et al, 1987; Rudy 1996; Soanes et al, 2000; Barrett et al, 2001; Browne et al, 2002; McIlfatrick & Keeney, 2003).

It is suggested that the high attrition rates observed in some Delphi studies would be totally unacceptable as a response rate for a normal postal questionnaire (Reid, 1988; Beretta, 1996). Furthermore, a 70% response rate for each round has been suggested as necessary to maintain the rigour of the technique (Sumison, 1998). It is, however, unclear whether this figure refers to 70% of the original sample or 70% of those who responded to the previous round. A 70% response rate is also very difficult to achieve and few postal questionnaires would achieve such a high response rate. Despite response rates of ≥70% in both round 2 and round 3 it is acknowledged that the low response rate in round 1 may have affected the validity of results.

The low response rate to round 1 was not, however, unexpected. It was noted in the study design that larger panel sizes are associated with higher attrition rates (Dodge &

Clark, 1977; Reid, 1988). Substantial numbers still responded to the first questionnaire and high response rates in rounds 2 and 3 strengthen the validity of results. Furthermore, the inclusion of different respondents in rounds 2 and 3 also increases inter-rater reliability.

Recruitment

The study may be criticised for recruiting participants from one professional interest group as this may have biased results. Respondents from varied backgrounds are recommended to guarantee a wide knowledge base (Delbecq et al, 1975; Rowe et al, 1991). Participants were, however, from different geographical areas and worked in a range of different haemato-oncology settings. The sample also contained substantial numbers of managers, educationalists and researchers in addition to practitioners fulfilling the criterion for varied backgrounds. Furthermore, the knowledge and experience of respondents demonstrated by the high numbers working directly with patients, the length of time most respondents had worked in the speciality and their post-registration educational qualifications also make transparent their credibility as experts in the speciality contributing to the validity of results (Kennedy, 2004).

Difficulties in Prioritising

Difficulties in prioritising topics were noted in round 2 and the number of questions overall and inequity in the number of questions in each category may have been a contributory factor. The wider range of responses in the larger categories supports this observation and it is possible that respondents were unable to retain all topics in memory (Mead & Moseley, 2001b).

In constructing the initial questionnaire much thought was given to trying to produce a questionnaire of reasonable length as it was recognised that too many topics could adversely affect consensus (Bond & Bond 1982; Schmidt, 1997; Browne et al, 2002). It was also acknowledged that an overly lengthy questionnaire was likely to increase attrition rates as busy nurses would be unlikely to find time for completion. Questionnaire length does, however, have to be balanced against the argument that excluding topics is likely to increase attrition. Respondents may not choose to complete a subsequent questionnaire if they find their original contribution has been ignored (Williams & Webb, 1994). Hasson et al (2000, p1012) support this view and argue that excluding topics "contradicts the basic tenets of the Delphi technique".

Reducing topics too much would also have resulted in the identification of very broad research themes encompassing numerous research questions. Previous Delphi studies have been criticised as unhelpful in developing research frameworks because of the "global and multi-faceted nature of the research issues identified" (Macmillan Practice Development Unit, undated p5). Furthermore, lengthy questionnaires also appear to be relatively common in other studies aiming to determine research priorities (Yates et al, 2002; Lee et al, 2003; Berger et al, 2005).

In designing the study great care was taken in trying to achieve a balance between retaining the richness of the original data and producing a second round questionnaire of a reasonable length. Yet, despite these efforts some of the research priorities identified are broad and multi-faceted. On reflection, producing a shorter questionnaire may have been advantageous. Yet, the consistency between the 33 highest rated topics in rounds 2 and 3 indicates that the length of the questionnaire did not adversely affect results.

Feeding Back Results

The results of the second round were fed back to respondents with the third round questionnaire. Consideration was given to whether respondents should be asked to prioritise all topics again in the third round or just those that reached consensus. Hasson et al (2000) suggest only feeding back those that reach consensus may force agreement and subsequently bias results. Following consultation with the expert panel regarding the different options the decision was made to present respondents with all 178 topics again. Retrospectively it might have been prudent to present only those topics that reached consensus as fewer topics may have increased agreement on priority topics. Good agreement was, however, achieved between the two rounds of the study and in retaining all topics in the third round the potential for bias was reduced. Furthermore, the high level of agreement between the two rounds strengthens the credibility of results.

Implications for Practice

Identification of priorities is of little value unless they are translated into programmes of research. Further exploration of priority areas is required but the priorities identified in this study provide a good starting point for further exploration and the development of research programmes in haemato-oncology nursing. It is astonishing that at least one topic was identified as a research priority 30 years ago and others a decade ago, yet little progress appears to have been made in addressing these issues. The scarcity of funding, small numbers of available researchers and lack of coordination of nursing research are likely explanations for this (Molassiotis, 1997a; Hunt, 2001; Richardson et al, 2001). It is, however, crucial to address these issues to develop a robust evidence base for haemato-oncology nursing practice. Without concerted leadership, commitment and action in progressing a coordinated strategy and programmes of research the same topics are likely to be identified as priorities in 10 years' time. Perhaps, more importantly we will remain unaware of the most effective interventions to improve patient care.

Development of research programmes requires strong leadership, coordination, commitment and cooperation from interested, energetic and dynamic individuals, professional interest groups and higher education institutions. Multi-professional research should be considered and may help to reduce replication of research and associated costs and also help to provide different perspectives (Richardson et al, 2002). A national research strategy would need to be developed to maximise research expertise and co-ordinated programmes of research.

Major challenges exist in both developing and implementing such a strategy. Development of strong collaborative arrangements between different institutions and multi-professional groups with interest and expertise in haemato-oncology would help increase opportunities for funding and strengthen proposals for funding. It is acknowledged that lack of funding and infrastructure will remain barriers to implementing a research strategy (Hunt, 2001). There would, however, appear to be an increased chance of success with a collaborative, multi-centre initiative.

Many hurdles and setbacks are likely to be encountered in developing programmes of research. The process will take a number of years to become established and sustained leadership, enthusiasm, commitment and effort will be required. To develop a robust evidence base for haemato-oncology nursing practice it is, however, imperative to address these challenges. Initial steps taken include presentation of results of the Delphi study at the RCN Joint Haematology and Bone Marrow Transplant Forum and Blood Transfusion Forum conference in October 2005 and publication of the results of the first 2 rounds of the study as a chapter in the textbook 'Nursing in Haematological Oncology (Grundy, 2006a). Discussions have also taken place with the RCN HMBT forum in relation to progressing the research agenda. Forum committee members are leaders both nationally and in their individual organisations and could help to both develop a research strategy and support its implementation.

Unfortunately, due to uncertainty regarding the future of the RCN professional forums discussions have not progressed as far as they could. The situation with the professional forums is, however, now more optimistic and it may be possible to recommence discussions in the near future. Other options do, however, exist and include discussing the possibility of collaborative research with other interested individuals across the UK. Additional publications of the results of all 3 rounds of the Delphi study in a professional journal are also planned in the near future.

Conclusion

This is the first study to explore research priorities across the entire spectrum of haemato-oncology nursing. The study has identified research topics practising nurses consider to be priorities and clear themes have emerged from the data with the potential to generate new knowledge and contribute to advancing knowledge for practice. It is acknowledged that the identification of research priorities is only the first step in developing the evidence base for haemato-oncology nursing and will, only contribute to advancing knowledge for practice if they are translated into a research strategy and programmes of research. It is also recognised that some of the research topics are broad and require refinement before programmes of research can be developed. The limitations of the study also require to be considered in interpreting results although the consistency of results between rounds 2 and 3 does lend strong support to their credibility. Results therefore appear to provide a firm foundation for developing a research strategy and programmes of research for haemato-oncology nursing.

Many of the topics identified are specific to haemato-oncology nursing but some are also relevant to the cancer nursing community and others would benefit from multi-disciplinary collaboration. These distinctions are important if the results of this study are to be acted upon and future research programmes developed. Before results can be acted upon they require to be disseminated to a much wider audience if coordinated and collaborative multi-centre programmes of research are to be developed. Discussion and collaboration between different groups of researchers is required before action can be taken in implementing the results of this study. Further dissemination of results and discussion with others is vital in developing future research strategies and achieving the aim of expanding and advancing the knowledge base for practice. Recommendations for achieving this are outlined in the subsequent chapter.

It is also recognised that translating the identified research priorities into a research strategy and programmes of research will be challenging and many obstacles are likely to be encountered. The small number of active researchers in the speciality and scarcity of research funding increase these challenges. Strong leadership incorporating energy, effort and persistence will therefore be crucial in engaging active and influential researchers in the development and implementation of a research strategy. Recommendations for addressing these challenges and reflection on my personal leadership development are therefore also explored and discussed in the subsequent chapter.

CHAPTER 8: CONCLUSION

Introduction

This doctoral project was undertaken as a means of contributing to expanding and advancing the knowledge base for nurses working in haemato-oncology. It is generally recognised that practising nurses require relevant, up-to-date, evidence based knowledge to provide effective nursing care. The rationale for the project resulted from my previous experience of editing the first edition of the textbook 'Nursing in Haematological Oncology'. This experience illustrated the paucity of research evidence specific to the speciality, the lack of comprehensive nursing textbooks and the limited number of formal education programmes. The development of a second edition of this text provided a further opportunity to increase the available knowledge resources by interpreting, synthesising and organising existing knowledge in a form that increased accessibility and therefore usefulness to practising nurses. I perceived that it also provided an opportunity to contribute to the development of new knowledge and the evidence base for practice by conducting a study to identify research priorities. Results from this study could be widely disseminated to practising nurses through inclusion as a chapter of the textbook. This chapter critically reflects on achievement of the overall aims of the project, my learning resulting from the experience of undertaking the project and concludes with recommendations for future development.

The aims of the project were to:

1. Contribute to expanding and advancing the knowledge base for nurses working in the speciality of haemato-oncology
2. Identify research priorities for haemato-oncology nursing
3. Edit and have published second edition of the textbook 'Nursing in Haematological Oncology'

Reflection on the Textbook

The project was ambitious in aiming to contribute to expanding and advancing the knowledge base for practice. Producing a published textbook certainly adds to the available sources of information that practising nurses can use to develop their knowledge. It is also congruent with the definition of knowledge as a form of knowing that can be shared or communicated with others (Chinn & Kramer, 2004). Furthermore, as the only British nursing text in the speciality the book makes a significant and valuable contribution to expanding and advancing the knowledge base for practice.

It is recognised that for knowledge to be useful to practising nurses it needs to be relevant and different types of knowledge are required. Textbooks are predominantly a source of empirical knowledge (Carper, 1978; Chinn & Kramer, 2004). Within this textbook much emphasis has also been placed on the evidence base for practice. The value of the textbook in advancing knowledge for nursing practice could therefore be questioned particularly as it is acknowledged that empirical knowledge cannot address the complexities of practice (Simmons, 1992). Furthermore, knowledge must be used and incorporated into practice to become valuable (Eraut, 1994).

Theoretical knowledge does, however, form the basis of all knowledge used in practice (Eraut, 1985). It is therefore essential to advancing the knowledge base for practice. I have also argued that while a textbook is mainly a source of empirical knowledge it can support and facilitate the development of other types of knowledge. Ethical theories and principles were included in the textbook and their use in individual situations with patients and their carers and reflection on practice informs clinical decisions. The socio-political context of care and the role of nurses in decision making and political influencing are also incorporated into the textbook. As raising awareness is the first step in becoming involved and changing attitudes (Rogers, 1983) it thereby contributes to expanding the knowledge base for practice.

The very nature of aesthetic and personal knowledge gained through action and interaction with others means they cannot be learned through the medium of a textbook. The limitations of the textbook as a source of knowledge for practice are therefore highlighted. Attempts were, however, made to facilitate the development of aesthetic and personal knowledge through the use of case studies, reflection points and discussion questions. These text features aimed to increase relevance to individuals' own practice, stimulate discussion and increase learning from text through the active use of knowledge. It does, however, have to be acknowledged that the extent to which these features contribute to advancing the knowledge base for practice is limited and they cannot replace actual experience with people and situations.

Reflection on personal, aesthetic and ethical knowledge incorporated into the textbook has highlighted the difficulties in truly representing or understanding the patient experience. In retrospect including case studies written by patients and family members would have increased understanding of their experience and help to improve the contribution of the text in supporting aesthetic and personal knowledge development. This has led to the recognition that any future editions of the textbook should attempt to balance the evidence base with real life experiences of patients and their families. Reflecting on the textbook as a source of knowledge has increased my understanding of the importance of the different types of knowledge for nursing practice. The need to integrate the different types of knowledge in advancing the knowledge base for practice has also been highlighted.

A state of the art text is considered to include the latest research evidence and other sources of knowledge while indicating what might be considered best practice for a particular speciality (Corner & Bailey, 2001). In developing the textbook the lack of robust research evidence underpinning the speciality was emphasised and detracts somewhat from the ability of the textbook to contribute to expanding and advancing the knowledge base for practice. The text does, however, bring together what is currently known and uses evidence from other relevant sources including, medicine, HSCT nursing and cancer nursing. Reflection and critique on the textbook has highlighted that the text has been written from a traditional biomedically focused perspective and the human experience of patients and their families is less evident. While the importance of evidence and scientific knowledge requires to be acknowledged it also needs to be balanced with the real life experiences of patients and their families. Reflection on the content of the text also revealed areas for expansion and further development particularly in relation to the experience of patients and their families and the elderly. Inclusion of these issues would certainly have enhanced the textbook and will be incorporated into any future editions.

Reflection on the textbook has revealed several limitations. No textbook is, however perfect and it is only one source of knowledge. Practising nurses require to use a range of resources to expand and advance their personal knowledge base. The textbook does have the advantage of assimilating, synthesising and interpreting a considerable amount of information and includes much of the current evidence base in one volume making it more accessible for practising nurses. It may therefore be considered a reasonably accurate account of what is known and overall appears to have achieved the aim of expanding and advancing knowledge for haemato-oncology nursing practice.

Reflection on the Experience of Editing the Textbook

My previous experience of editing distance learning materials and other published texts was a major influence in the editing of the textbook. In hindsight my previous experience had, however, resulted in a familiarity with the process and it was personally challenging to engage in reflection at a higher level. Before undertaking the doctoral project most of my learning related to writing and editing had been experiential. Undertaking the doctoral project necessitated investigation of previously unexplored theoretical perspectives and further exploration of more familiar theories. Educational psychology and moving from the known to the unknown are fundamental in teaching and learning (Quinn, 1995). Despite being well aware of these concepts I had not been consciously aware of using them in preparing the textbook. One explanation for this is the internalisation of knowledge through frequent use. Theoretical knowledge and experience are perceived to be synthesised to create tacit knowledge/intuition (McCutcheon & Pincombe, 2001; Welsh & Lyons, 2001). Reflecting on the development of the textbook has reawakened my awareness of these educational theories. It has also resulted in revisiting and developing my knowledge of information processing theories and introduced me to new ideas related to comprehension and cohesiveness of text. This knowledge will be invaluable in future writing and editing ventures.

Particularly insights relate to the appropriateness of text in relation to the target audience. When the initial edition of the book was conceived the target audience were clearly identified as those working in areas where haemato-oncology was combined with another speciality rather than specialist nurses. In editing the text I perceived I possessed a reasonably good idea of the level of previous knowledge of the average reader. Reflecting on the depth and level of the content I have realised that the expert knowledge of chapter authors and my knowledge as editor has probably affected my objectivity in relation to the previous knowledge of readers. It is therefore possible that the level of the text is too high for non-specialist nurses. In retrospect, my familiarity with the editing process reflected a tendency towards complacency. A situation that is well recognised as reducing the stimulus for higher levels of reflection and double loop learning (Argyris, 1991). My increased awareness of this pitfall will ensure increased consideration and questioning of the appropriateness of information for the intended audience in future editing tasks. It is, however, difficult and time consuming to constantly question work that you are involved in on a regular basis. Working with others can introduce fresh ideas and new perspectives and this would certainly be something that I would consider in future editing projects as a means of stimulating further reflection.

In essence, editing a multi-author text is a project that requires to be managed like any other project. My approach to editing the text did not, however, mirror the project management approach as well as it might. Influenced by previous experiences I anticipated problems arising with individual chapter author's adherence to timescales but perceived I had little control over this. I therefore did not consider alternative solutions at the beginning of the project and my responses to non-submission by the agreed timescale were reactive. Good project management anticipates problems in the planning of the project and puts contingency plans in place to minimise their impact on the outcome and timescales of the project (Grundy, 2002) . The opportunity to reflect on the editing process has helped me to revise my thinking on this issue. It is recognised that life is unpredictable and unanticipated situations will arise in any project that will affect outcomes. Being more proactive at the beginning of the project and keeping in regular contact with chapter authors in the time between commissioning and the deadline for submission of the first draft could, however, help to address some of these issues. Addressing the issues as soon as they are identified and offering more practical support when individual authors are struggling with the writing task and meeting deadlines may also be helpful in future similar ventures.

The previous experience and writing skills of chapter authors will obviously differ in any multi-author text. In editing the textbook it was difficult to determine the perceived support needs of contributors and therefore offer the right practical support at the right time. Determining the perceived support needs of authors in relation to their writing skills and offering practical support at the beginning of the process may therefore be a useful strategy for improving management of the project. Providing support in this way is likely to increase the pool of potential authors and is regarded as a function of nurse leaders (Mateo & Meeker, 1992). Increasing support would, however, be time-consuming for the editor (Mateo & Meeker, 1992; Burnard, 2004). Most of the editing of the textbook was undertaken in my own time therefore the time required to increase support would be impossible to achieve without increasing the timescales for the project. This would also increase the potential for the text to be out of date by the time it is published. The importance of support should not, however, be underestimated and reflection on these issues has led to the identification of alternative means of providing support. These include partnership with a second editor who could share the workload and jointly authored chapters with an experienced author supporting a novice author. These alternatives would require effort to implement but would produce benefits for both the development of individual authors and the efficiency of the editing process.

The opportunity to reflect on the experience of editing the textbook has provided some valuable insights into how I approach such projects and how familiarity can produce complacency. Fresh perspectives on leading, managing and developing a multi-author text have been gained. These insights will act as a reminder of the need for careful consideration of alternatives in the planning stage of future projects and a stimulus for continually questioning my approach to all projects.

Reflection on the Identification of Research Priorities

The literature review highlighted the need for research to inform the effectiveness of patient care and improve outcomes. Previous nursing literature reviews in haemato-oncology have focused on HSCT and no previous literature reviews appears to have been conducted across the entire spectrum of haemato-oncology nursing. The review identified a low volume of research studies conducted between 1996-2006 with the majority focusing on HSCT. Furthermore, over 50% of studies were encompassed in the overarching themes of quality of life, patient experience, side-effects of treatment and psychological effects and adaptation. Few other studies focused on the same topic and different approaches and measurement instruments used in the studies that did explore the same topic made comparisons between studies difficult. Contradictory findings, lack of replication and small sample sizes also detracted from the quality of the research. A fragmented and uncoordinated approach to research in the speciality therefore emerged.

It is recognised that political drivers influence research direction and financial support but there appeared to be little focus on political drivers in the research conducted. For example only 6 studies focused on the patient experience and there was little indication of patient involvement in research processes. Furthermore, few studies focused on nurse led care, role expansion or changes in service delivery to improve the efficiency and effectiveness of services with the few studies that did address these issues being from the North American literature. It is possible that this lack of focus on research related to political drivers may have adversely affected the funding and resources attracted to research in the speciality.

Many gaps became apparent in the existing research base and the predominance of research focusing on HSCT means that to date research has mainly included a younger age group and those with a better prognosis. Haematological cancers mainly occur in the elderly and research addressing their needs or nursing interventions appears to be virtually non-existent. In common with the general cancer nursing literature little research exists relating to the effectiveness of nursing interventions or organisational and role development (Richardson et al, 2001; 2002).

This fragmented and uncoordinated approach is common to many aspects of nursing research (Corner, 1993, Hunt, 2001). This situation cannot be changed quickly but requires a sustained and coordinated approach to future research if the evidence base for practice is to be expanded and advanced. The literature review revealed some direction for future research but insufficient information to allow identification of research priorities. Support was therefore provided for a study to identify research priorities as a first step in developing coordinated future research strategies and programmes.

Reflection on Research Methodology

Before undertaking this study my research experience was relatively limited. Undertaking the study therefore formed a significant part of my learning. It is, however, suggested that it is not until you have used the Delphi technique that its difficulties and challenges become apparent (Keeney et al, 2006). This was certainly the case with this study.

The Delphi technique is an unusual research method as no universal guidelines exist and decisions require to be made in the context of the study (Hasson et al, 2000). The literature associated with the number of rounds, criteria for the expert panel, sample size and consensus was scrutinized and given careful consideration in designing the methodology for the study. A low return on the first questionnaire was anticipated and for this reason a large sample was initially invited to participate. In designing the study I was convinced that I had thought through all the issues carefully.

Despite the perception that I understood the principles of the Delphi technique and how it should be operationalised several unanticipated issues arose during the course of the study. This is congruent with the iterative nature of the Delphi study highlighted in preceding chapters and the need to make decisions as the research progresses. Although large amounts of qualitative data were anticipated initially I had envisaged that there would be some similarities between potential research topics and did not anticipate the diversity of responses. This diversity of responses made it difficult to produce a second round questionnaire of reasonable length. I did have concerns about the length of the questionnaire but found it difficult to determine how to reduce it further without losing the richness of data. In retrospect, however, the length of the questionnaire may have contributed to attrition rates.

A further unexpected development in the study was the close clustering of responses in round 2 and therefore the need to undertake a third round. The need to undertake a further round affected the timescales for the study and due to publication deadlines only the first 2 rounds of the study could be included in the textbook. Decisions had to be made regarding the third round including the format of the questionnaire and the method of prioritisation. All decisions taken in relation to the study were discussed with the expert panel and the project supervisors. While this support helped the decision making process these individuals were not as immersed in the data as myself. One aspect of the study that was overlooked in designing round 3 was analysis of the data. Changing the method of prioritisation made robust statistical comparison between rounds 2 and 3 impossible. This experience has emphasised the importance of statistical advice in relation to data analysis and the changing context of a study. Furthermore, the unanticipated developments within the context of the study have been valuable learning experiences and will certainly help to inform the design and conduct of future research initiatives.

In future research I would strongly favour a co-researcher who was equally familiar with the data and with whom decisions could be discussed. Undertaking this study has highlighted my novice researcher status and provided me with further insight into the need to work with other more experienced researchers for my future development.

Reflection on Results

The diversity and number of research topics obtained from round 1 may demonstrate practising nurses' awareness of the lack of research underpinning haemato-oncology nursing. Many of the topics identified, however, also appeared to be related to educational needs. Further exploration of this observation was not found to be feasible as indicated by the results of the pilot study undertaken between rounds 1 and 2. Several topics identified in the final list of research priorities do, however, indicate an educational focus. It is recognised that this is my interpretation of results and further exploration of the priority topics and how practising nurses interpret them would be valuable.

Priority research topics identified in rounds 2 and 3 demonstrated remarkable consistency. The limitations of the study obviously need to be taken into consideration but the high response rates in rounds 2 and 3 and the consistency of results between rounds provides strong support to their credibility as topics that practising nurses perceive to be research priorities thereby achieving the aim of identifying research priorities for haemato-oncology nursing. The credibility of results is also enhanced by the attributes of respondents as individuals with the requisite knowledge and experience to identify research priorities in haemato-oncology and because of the different methods of prioritisation used in the 2 rounds. It is, however, recognised that many of the research topics are broad and will require further exploration and refinement to develop relevant research questions. Furthermore, it is important that research topics that address political drivers are considered in future research to maximise the potential for attracting funding and resources.

For study results to be meaningful they do, however, require to be acted upon and the findings have implications for education, practice and research. The research themes emerging from the data provide a useful starting point for the development of future research strategies and programmes of research. The need for collaboration with others to take forward common areas of research interest has also been noted. For study results to be meaningful they do, however, require to be acted upon and the findings have implications for education, practice and research.

Implications for Practice, Education and Research

Future Actions

It has been noted in the preceding chapter that identification of priorities is of little value unless they are translated into programmes of research. The priorities identified in this study provide a good starting point for further exploration and the development of research programmes in haemato-oncology nursing. Developing structured, strategic, planned programmes of research is seen as vital at international, national and local levels to ensure research develops in a coordinated way and scarce resources are used in the most appropriate manner (Corner 1993; Hunt 2001; Richardson et al, 2001; Kearney, 2002).

Yet, before programmes of research can be identified findings of the study require to be disseminated to a wider audience. To date, findings of the first two rounds of the study have been published in the textbook and findings of all 3 rounds have been presented at a national RCN haemato-oncology conference. Preliminary discussions have taken place with key members of the RCN HSCT forum in relation to taking the results forward but organisational restructuring and uncertainty has precluded any further action. Those aware of the results of the study are therefore currently limited. In raising awareness further publication in professional journals is planned in the near future with specific actions outlined in Figure 2.

Results also need to be disseminated to key research leaders in haemato-oncology and cancer nursing. I already have good working relationships and extensive networks with leading nursing researchers in both cancer nursing and haemato-oncology and plan to inform them of results and initiate discussions for acting on results and developing coordinated programmes of research. A Scottish clinical oncology nurses research group is holding its inaugural meeting in June 2008 hosted by the National Research Institute for Scotland and I plan to disseminate results of this study and discuss the development of a research strategy and programmes of research at this meeting.

The challenges to taking forward a research strategy and programmes of research including the scarcity of research funding and small number of active researchers in the speciality have been acknowledged in preceding chapters. My research output and reputation are currently low and collaboration with much more experienced and high profile researchers will be required if a research strategy and programmes of research are to be successfully developed and crucially funding is to be attracted. Leadership skills and the ability to influence and persuade both experienced researchers and practising nurses of the importance and relevance of results will be a key part of my role in successfully ensuring the results of this study are acted upon. There is power in numbers and the more people who are actively supportive of building programmes of research from the results, the greater likelihood of achieving success (Abood, 2007). In this project I would plan to draw on my extensive personal networks and endeavour to influence individuals with a high research profile to champion this project. I do, however, recognise that raising my research and leadership profile is necessary for my own personal development.

Research, Education and Practice Links

Research, education and practice are inextricably entwined. Involvement in research is not only concerned with conducting research but also incorporates implementing research into practice and education. Several priority topics imply educational needs in their emphasis on the need for guidelines. These results may indicate a lack of awareness of previous research and the need for education. Alternatively they could be interpreted as recognition of the inconclusiveness of the current evidence base and the increasing demand for evidence to support practice. The latter explanation appears to be most likely as the topics identified are those that, from experience, I would personally have predicted haemato-oncology nurses would identify as problematic.

Conducting systematic reviews and development of clinical guidelines and best practice statements is a further means of acting on the results of the study. Such developments would help raise awareness of existing research, contribute to supporting practising nurses to implement research into practice and encourage collaboration between educationalists, researchers and practitioners. Producing guidelines, systematic reviews and best practice statements is only useful if practising nurses are aware of them and they are implemented into practice and used to improve outcomes for patients, and the efficiency and effectiveness of nursing interventions and service delivery. Education and support are, however, required to support successful implementation into practice (Duff et al, 1996). Programmes of education encouraging cancer nurses to develop such skills are invaluable and benefit both the individual nurse and their workplace. The need for education for practising nurses and the importance of implementing research into practice has, however, been advocated and emphasised for many years. Actual implementation of research into practice is, however, more difficult to achieve.

An innovative collaborative approach to implementation has been developed by the Joanna Briggs Research Institute (JBI) based in Adelaide but with global collaborative sites all requiring an academic and clinical partnership (JBI, 2008). JBI produce systematic reviews with recommendations for practice. Reviews are evaluated in practice for variability, health outcomes and cost. Following an evaluation report best practice guidelines are produced and shared internationally. The commitment and support available for implementing evidence based practice increases the potential for successful implementation. Furthermore, practising nurses become actively involved in the implementation of research and the process of evaluation.

A formal collaboration between JBI and NHS Quality Improvement Scotland (NHS QIS) has recently been agreed with an active link with each Health Board in Scotland. Dissemination of study results to this collaboration and influencing and persuading them of the importance of results will be a key factor in developing systematic reviews, guidelines, best practice statements and acting on study findings.

Developing Future Researchers and the Evidence Base

The increase in practitioners undertaking masters degrees has been cited as one reason for the increased the number of small studies and in the cancer nursing literature and the fragmented approach to research (Richardson et al, 2001; Hunt 2001). Educators therefore have a responsibility to encourage students undertaking masters and doctoral level studies to contribute to ongoing programmes of research. To achieve this educators working in different institutions will need access to up-to-date information about research programmes, ongoing research and research priorities. One means of achieving this and supporting the implementation of the results of this study would be to develop an on-line resource that could be contributed to and accessed by educators, practitioners and researchers nationwide. The facility to host such a resource already exists on the NHS Education for Scotland (NES) website. Discussions regarding the value of such a resource and the practicalities of development will be discussed with educators, researchers and practitioners in the speciality and also more widely with professional colleagues in NES.

Disseminating the results of this study, engaging others and stimulating their enthusiasm for acting on the results will be challenging requiring hard work, persistence, energy and leadership. I am well aware of my persistent nature but recognise that I require further development in leading at a more strategic level. Reflection on my leadership journey through the doctoral programme is therefore undertaken to facilitate identification of my future development needs.

Reflection on my Journey to Research Leadership

At the beginning of the doctoral programme despite having led projects including developing the proposal and editing the first British haemato-oncology nursing textbook and chaired professional groups and conferences at a national level I did not regard myself as a leader. Reflection on my leadership attributes led to the recognition of my ability influence, motivate and inspire others and make a difference although I would not have been able to articulate how I did this. Reconsidering these experiences at the start of the leadership module emphasised the importance of communication, empowerment, teamwork and collaboration in working towards organisational goals in leadership effectiveness (Hogan et al, 1994). It also made me question my own capabilities in these areas and how I could further develop them in the future.

During the doctoral programme I have also become increasingly aware that engagement with others to achieve a shared vision is recognised as a key factor in effective leadership and appears to be closely related to motivation and influencing (Alimo-Metcalfe & Alban- Metcalfe, 2004; Towers Perrin, 2005a & b). Engagement with others in a meaningful way can be difficult in the NHS where the focus in on getting the job done. I am also aware of my own tendency to focus on getting the job done particularly when under pressure to meet deadlines. Becoming more aware of these issues through reflection and being enlightened through revelations of unconscious processes and defensive behaviours (Huffington et al, 2004) has allowed me to develop alternative perspectives, experiment with and incorporate different strategies for managing resistance and reducing conflict into my work thereby developing my leadership skills.

Engagement with others in terms of developing myself and my research expertise has been a regular theme throughout this conclusion. Furthermore, development and implementation of a research strategy and programmes of research cannot be achieved by one person working alone. The concerted, and organised efforts of many will be required over a substantial time period (Corner, 1993). Engagement with others will therefore be vital particularly in influencing and motivating people to become involved and most especially in the development of collaborative research programmes. Development of effective partnerships is perceived to be an important means by which research leaders can achieve successful outcomes (Fitzsimons et al, 2006). It is also important to include health care providers and patients and carers in such partnerships. Engagement with others will therefore be essential in convincing others of the value of the results of this study and encouraging collaboration in developing a research strategy and programmes of research.

Much of my leadership development throughout the doctoral programme has been associated with developing leadership skills within the work context and leading teams. Less attention has been placed on the attributes of strategic or political leadership. Transferable aspects do exist although there are also some aspects of leadership that I will need to develop further to ensure the successful development and implementation of a research strategy.

It is suggested that one way to view political leadership is through consideration of levels of influence (Antrobus, 2003). Certainly in developing and implementing a research strategy influence is needed at different levels. Those researchers and fellow collaborators that would be involved in strategy development and those at a higher national or political level who you would want to champion the development. Having a group of people who are passionate about an issue and truly believe it will make a difference will support influencing at a higher level. Influencing also requires the ability to communicate your message clearly and succinctly through lobbying, knowing the key players and who to influence, referent power through credibility and respect, self-belief and self-confidence (Rafferty & Traynor, 2004; Fradd, 2004; Abood, 2007). The ability to read the policy agenda and be able to present ideas in a timely fashion that are congruent with the government agenda is also likely to contribute to success (Rafferty & Traynor, 2004). Further development of my leadership skills in targeting the key players, presenting a clear, succinct message, negotiating and lobbying and probably most crucially self-confidence and self-belief will be beneficial to this process. Actions for my personal development are included in Figure 3.

It is possible that the time is right politically to present the findings of the Delphi study and a research strategy. Strategies for increasing nursing research capacity in the UK have been recently published (UKCRC, 2007). Furthermore, cancer is still high on the political agenda as demonstrated by the recently published cancer reform strategy (DH, 2007b). Implementation of these publications may provide the opportunity to raise the profile of the haemato-oncology nursing agenda, emphasise the paucity of the current evidence base and the urgent need for research to improve patient outcomes and the efficiency and effectiveness of nursing interventions and service delivery.

Concluding this project does not therefore conclude the business of expanding and advancing knowledge for haemato-oncology nursing practice. Although the aims of the project been met, the work started within this doctoral programme requires to be continued. The leadership, energy, continued commitment and persistence required to achieve this will also contribute to my further learning and development.

Figure 2: Action Plan for Findings

Action	Rationale	Timescales
Disseminate results to a wide audience. Write articles for publication in European Journal of Oncology Nursing and Nursing Standard.	Publication of results highlights their importance. No action will be taken to implement results if no-one knows about them.	Articles prepared and submitted by Aug 2008.
Present results of study to clinical oncology nurses network group and National Research Institute for Scotland. Inform leading researchers in speciality of results of study and initiate discussion regarding development of a research strategy and programmes of research.	Highlight the findings of the study and influence others to support implementation of a research strategy with view to influencing at a higher political and strategic level.	Initial meeting 13/06/08 End June 2008
Write to JBI and NHS QIS collaborative to highlight study findings including the paucity of research underpinning haemato-oncology and promote importance of results.	Influencing and persuading JBI/NHS QIS to conduct systematic reviews and support the evaluation of recommendations for practice for identified priority topics would be a major advance in implementing evidence into practice and for education.	Initial discussions with JBI/NHS QIS by Oct 2008.
Explore the feasibility and practicalities of developing an on-line resource of research programmes with educators, researchers and practising nurses in the speciality.	Would help to improve coordination of research and contribute to ongoing research programmes.	By end Oct 2008.

Figure 3: Action Plan for Author

Action	Rationale	Timescales
Explore alternative options for influencing at a higher strategic and political level and plan future development.	Further develop higher level strategic and political leadership skills	By Sept 2008.
Further develop research skills through working in partnership with other more experienced researchers.	Experiential learning valuable and supports development of empirical knowledge gained from formal learning	Explore options by end Dec 2008.
Explore methods of further developing self-belief and self-confidence and plan future development.	Would help to further develop leadership skills at all levels.	By Sept 2008.

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APPENDICES

APPENDIX 1:
Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Appendix 1: Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Book	Content	Mapping of Content to 'Nursing in Haematological Oncology'
Bakitas Whedon & Wujcik, 1997. Blood and Marrow Stem Cell Transplantation: Principles Practice, and Nursing Insights	Bone marrow to blood stem cells, past, present, future.	Chapters 3, 5, 13, 31
	Hematopoiesis	Chapter 1
	Transplant immunology: HLA and Issues of stem cell donation	Chapters 1 & 13
	Blood and marrow stem cell transplantation: indications, procedure, process	Chapter 13
	Pharmacologic and biological agents	Chapters 2, 3, 9, 13
	Radiation therapy in transplantation	Chapters 10 & 13
	Genetics and gene therapy	Chapters 1 & 11
	Graft-versus-host disease	Chapter 13
	Hematologic effects of transplantation	Chapters 13, 15 &16
	Gastrointestinal effects	Chapters 13, 17, 18
	Pulmonary and cardiac effects	Chapter 13
	Neurological effects	Chapter 13
	Renal and hepatic effects	Chapter 13
	Psychosocial effects: Pretransplant and acute treatment phase	Chapters 13 & 23
	Fertility and sexuality issues	Chapters 13, 20 & 21
	Quality of life after transplantation	Chapters 13 & 25
	Patients' perspectives	-
	Family issues and perspectives of transplantation	Chapters 7, 8, 13, 24
	Transplant networks and standards of care: International perspectives	-
	Nursing research in blood cell and marrow transplantation	Chapter 30
	Ethical issues of transplantation	Chapters 4, 6, 7, 8, 9, 11, 20, 23, 24, 26, 27, 28, 29,30
	Models of ambulatory care for blood cell and bone marrow transplantation	Chapter 31

Appendix 1 continued: Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Book	**Content**	**Mapping of Content to 'Nursing in Haematological Oncology'**
Kearney & Richardson 2006. Nursing Patients with cancer: Principles and Practice	Decision making in cancer care	Chapter 11, 23, 27
	The experience of cancer treatment	-
	Chemotherapy	Chapter 9
	Radiotherapy	Chapter 10
	Biological therapy	Chapter 11
	Bone marrow transplantation	Chapter 13
	Complementary and alternative therapies	Chapter 23
	Haematological support	Chapter 12
	Nausea and vomiting	Chapter 17
	Pain	Chapters 5 & 13
	Constipation and diarrhoea	Chapters 5, 9 & 13
	Breathlessness	-
	Skin and wound care	9, 13, 14, 15
	Lymphoedema	Chapter 6
	Oral complications	Chapter18
	Alopecia	Chapters 21, 23
	Malignant effusions	-
	Anorexia, cachexia and malnutrition	Chapter 19
	Cancer-related fatigue	Chapter 22
	Impact of cancer and cancer therapy on sexual and reproductive health	Chapters 20 & 21
	Altered body image	Chapters 21 23
	Psychological care for patients with cancer	Chapters 7, 8, 13, 23
	Intensive nursing care of the patient with cancer	Chapter 13, 24
	Cancer care and cancer nursing	-
	Rehabilitation and survivorship	Chapter 25
	Palliative care	Chapter 7, 8, 26

Appendix 1 continued: Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Book	**Content**	**Mapping of Content to 'Nursing in Haematological Oncology'**
Corner & Bailey, 2001. Cancer Nursing: Care in Context.	Knowledge and caring	-
	Impact of cancer	Chapters 23, 24, 25, 27
	Impact of cancer on family	Chapter 20, 21, 24
	Impact of cancer on health care professionals	Chapters 28, 29
	Therapeutic strategies in cancer care	-
	Experience of treatment	-
	Chemotherapy	Chapter 9
	Radiotherapy	Chapter 10
	Endocrine therapies	-
	Complementary therapies	Chapter 23
	Hereditary cancer	-
	Developments in cancer treatment	Chapter 11 & 31
	Pain	Chapters 5, 13
	Nausea and vomiting	Chapter 17
	Fatigue	Chapter 22
	Breathlessness	-
	Wound management	-
	Lymphoedema	Chapter 6
	Malignant ascites	-
	Bone marrow suppression: infection and bleeding	Chapters 15 & 16
	Compromised nutrition	Chapter 19
	Altered self-concept	Chapters 21 & 23
	Sexuality and cancer	Chapters 21 & 23
	Anxiety and depression	Chapter 23
	Confusion	-

Appendix 1 continued: Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Book	Content	Mapping of Content to 'Nursing in Haematological Oncology'
Corner & Bailey, 2001. Cancer Nursing: Care in Context (cont)	Rehabilitation and long-term effects of treatment	Chapters 9, 10, 13 & 25
	Acute events in cancer care	Chapters 5, 6, 15, 13, 16
	Needs of children and adolescents	Chapters 7 & 8
	Needs of older people	-
	Needs of people from minority ethnic groups	Chapter 21
	Palliative care	Chapter 26
	Health services and cancer care	Chapter, 7, 8, 13, 20, 23, 26, 27, 28, 29, 31
	Research and cancer care	Chapter 30
Provan 2003. ABC of Clinical Haematology.	CML	Chapter 4
	The acute leukaemias	Chapter 4
	Myelodysplastic syndromes	Chapter 2
	Multiple myeloma and related conditions	Chapter 5
	Malignant lymphomas and CLL	Chapters 4 & 6
	Blood and marrow stem cell transplantation	Chapter 13
	Haematological disorders at the extremes of life	Chapter 7
	Haematological emergencies	Chapters 5, 6, 16
	The future of haematology: the impact of molecular biology and gene therapy	Chapters 11 & 31
Hoffbrand et al, 2001. Essential haematology	Haematopoiesis	Chapter 1
	Aplastic anaemia and bone marrow failure	Chapter 3
	Stem cell transplantation	Chapter 13
	The genetics of haematological malignancies	Chapters 1, 3, 4
	Acute leukaemias	Chapter 4
	CML & Myelodysplasia	Chapters 2 & 4
	The CLLs	Chapter 4
	Malignant lymphomas	Chapter 6

Appendix 1 continued: Mapping of Content of Related Texts to 'Nursing in Haematological Oncology'

Book	**Content**	**Mapping of Content to 'Nursing in Haematological Oncology'**
Hoffbrand et al, 2001. Essential haematology	Multiple myeloma and related disorders Blood transfusion	Chapter 5 Chapter 12
Hughes-Jones et al, 2003. Lecture notes on haematology	Haemopoiesis Structure and function of lymphoid tissue Lymphomas Classification of lymphomas Lymphomas (including ALL and CLL) Myeloma and other paraproteinaemias Neoplastic disorders of myeloid cells BMT Aplastic anaemia Blood transfusion and Haemolytic disease of the Newborn	Chapter 1 - Chapter 6 Chapter 6 Chapters 4 & 6 Chapter 5 Chapter 4 Chapter 13 Chapter 3 Chapter 12

APPENDIX 2:
Organisation of Nursing Research in Haemato-Oncology 1996-March 2006

Appendix 2: Organisation of Nursing Research in Haemato-oncology 1996-March 2006

Individual Adaptation to Wellness and Illness		
Topic	**Number of studies /Population**	**Authors**
Quality of Life	9 HSCT 1 lymphoma 2 leukaemia 1 leukaemia/ lymphoma 1 myeloma	Molassiotis et al, 1996a; Molassiotis & Morris 1998, 1999 ; Edman et al, 2001; Hacker & Ferrans, 2003; Byar et al, 2005; Gaston-Johansson & Foxall, 1996; Larsen et al, 2003; Beser & Oz, 2005; Bertero et al, 1997a & b; Persson et al, 2001; Poulos et al, 2001; So et al, 2003.
Patient experiences	6 HSCT 2 leukaemia/lymphoma 1 leukaemia 2 myeloma/HSCT	Thain & Gibbon, 1996; Stephens, 2005; Cohen & Ley, 2000; Jones & Chapman, 2000; Cooper & Powell, 1998; Persson & Hallberg, 2004; Persson et al, 1997; Bertero, 1998; Shuster et al, 1996; Coon & Coleman, 2004a & b
Side effects of treatment Symptom occurrence, intensity and distress	1 lymphoma 1 HSCT	Sitzia et al, 1997 Larsen et al, 2004
Pain	3 HSCT	Pederson & Parran, 1999a & b; David & Musgrave, 1996
Oral mucositis	2 HSCT/leukaemia 1 HSCT/myeloma/ lymphoma	Borbasi et al, 2002; McGuire et al, 1998; Salvador, 2005
Fatigue & depression	1 HSCT	El-Banna et al, 2004
Fatigue	1 HSCT	Molassiotis, 1999a
Anorexia & weight loss	1 long term survivors	Molassiotis, 2003
Psychological effects and adaptation	8 HSCT	Molassiotis et al, 1996b; Molassiotis, 1996; Molassiotis, 1997b; Molassiotis et al, 1997; Fife et al, 2000; Saleh & Brockopp, 2001a; Bywater & Atkins, 2001; Cohen et al, 2000
	Total 44	

Appendix 2 continued: Organisation of Nursing Research in Haemato-oncology 1996-March 2006

Family Adaptation to Wellness & Illness		
Topic	**Number of studies/ Population**	**Authors**
Family donor experiences	1 HSCT	Christopher, 2000
Experience of spouses	1 leukaemia/ lymphoma	Persson et al, 1998
Effect of massage & healing touch on anxiety, depression and caregiver burden	1 HSCT	Rexilius et al, 2002
Needs and experiences of family care givers	1 HSCT	Stetz et al, 1996
Emotional responses and needs of caregivers	1 HSCT	Grimm et al, 2000
Burden and health outcome of family caregivers	1 HSCT	Foxall & Gaston-Johansson, 1996
Changes in everyday family life	1 haematological cancers	Elmberger et al, 2002
	Total 7	
Supporting and Non-Supporting Environments		
Experiences of protective isolation	1 HSCT	Gaskill et al, 1997
Infection rates with and without protective isolation	1 HSCT & AML	Mank & van der Lelie, 2003
Reasons for unscheduled admissions post-HSCT	2 HSCT	Grant et al, 2005; Coleman et al, 2002
Determine effects of home HSCT on patient satisfaction with care, financial costs & pressure on inpatient accommodation	1 HSCT	Herrmann et al, 1998
Perceptions of quality of life, quality of care & patient satisfaction with home high dose chemotherapy & HSCT	1 HSCT	Schulmeister et al, 2005
	Total 6	
Physiological Interventions		
Fatigue and fatigue relieving strategies	1 HSCT 1 myeloma	So & Tai, 2005 Coleman et al, 2003
Self-administration of pamidronate	1 myeloma	Johannsson et al, 2005
Comparison of central venous catheter dressings	1 HSCT	Brandt et al, 1996
Use of complementary and alternative medicines	1 haematological cancers	Molassiotis et al, 2005
Effects of different HSCT, stem cell mobilisation & isolation procedures on infection, mucositis & variety of other factors.	1 lymphoma/breast cancer	Greco et al, 1996
Effects of opioid tapering guidelines on pain and withdrawal symptoms	2 HSCT	Pederson & Parran, 2000; Parran & Pederson, 2002
	Total 8	

Appendix 2 continued: Organisation of Nursing Research in Haemato-oncology 1996-March 2006

Psychosocial Interventions		
Topic	**Number of studies/ Population**	**Authors**
Effects of relaxation breathing exercise on fatigue, anxiety, depression and leukocytes	2 HSCT	Kim & Kim, 2005a Kim & Kim, 2005b
Interpersonal needs expressed by patients	1 HSCT 1 leukaemia	De Carvalho et al, 2000 Bertero & Eriksson 1996
Identification of empowerment strategies used in coping with illness	1 haematological cancers	Bulsara et al, 2004
Identification of most appropriate means of breaking news of patients' death to unrelated donors	1 HSCT	Atkinson, 2005
Effects of music on nausea and vomiting	1 haematological cancers	Ezzone et al, 1998
Outcomes of touch therapies	1 HSCT	Smith et al, 2003
	Total 8	

Professional Foundations for Practice		
Topic	**Number of studies/ Population**	**Authors**
Evaluation of emotional difficulties screening tool	1 HSCT	Molassiotis, 1999b
Evaluation of quality of life survivors' tool	1 HSCT	Saleh & Brockopp, 2001b
Validation of nursing diagnosis, anxiety	1 HSCT	Young et al, 2002
Nurses' experiences with DMSO	1 HSCT	Prior et al, 2000
Assessment of informed consent practices	1 HSCT	Goldberg & Musgrave, 1996
Development of a tool to plan staffing levels and assess workload	1 haemato-oncology wards	Colombo et al, 2005
Evaluation of burnout and job satisfaction	1 HSCT nurses	Molassiotis & Haberman, 1996
Identification and description of nursing diagnoses	1 leukaemia	Courtens & Abu-Saad, 1998
Knowledge, beliefs and attitudes to pain management	1 HSCT nurses	Pederson & Parran, 1997
Health care professionals' perceptions of palliative care in HSCT patients	1 HSCT nurses/doctors/palliative care CNS	McDonnell & Morris, 1997
	Total 10	

APPENDIX 3:

Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Appendix 3: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Gaston-Johansson & Foxall, 1996	Psychological correlates of QoL across the autologous BMT experience	Quantitative/ Descriptive/Correlational	24 lymphoma	Multiple data collection points
Bertero et al, 1997a	A substantive theory of quality of life of adults with chronic leukaemia	Qualitative/Grounded theory	15 CML/CLL	Semi-structured interviews. One data collection point
Bertero et al 1997b	Explaining different profiles in quality of life experiences in acute and chronic leukaemia	Qualitative Secondary analysis. Retrospective	23 total – 8 acute/15 chronic leukaemia	One data collection point
Molassiotis & Morris 1998	The Meaning of QoL and the Effects of Unrelated Donor bone marrow transplants for CML in adult long term survivors	Qualitative	28	One data collection point at least I year post BMT
Molassiotis & Morris, 1999	Quality of Life in patients with chronic myeloid leukaemia after unrelated donor bone marrow transplantation	Quantitative/Descriptive	28 CML/HSCT	One data collection point. Average 41.2 months post HSCT
Edman et al, 2001	Health-related quality of life, symptom distress and sense of coherence in adult survivors of allogeneic stem-cell transplantation	Quantitative. Mailed questionnaires	25 haematological cancers	2-4 years post HSCT—results compared to Swedish population norm (record review)
Persson et al, 2001	Acute leukaemia or highly malignant lymphoma patients' quality of life over two years: a pilot study.	Qualitative/quantitative	21 – 10 leukaemia/11 lymphoma	Multiple data collection points.

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Hacker & Ferrans, 2003	Quality of life immediately after PBSCT	Qualitative/quantitative descriptive/exploratory/ longitudinal	16	Multiple data collection points.
Larsen et al, 2003	Symptom distress, functional status and health related QoL before high dose chemotherapy with stem cell transplantation	Quantitative, comparative	51 mixed haem cancers/breast cancer	One data collection point – on admission for HSCT
Byar et al, 2005	QoL 5 or more years post-autologous hematopoietic stem cell transplant	Quantitative/descriptive/ correlational	92 mixed haem & solid tumour	One data collection point
Beser & Öz 2005	QoL in lymphoma patients	Quantitative/descriptive	80 lymphoma	Before initial chemotherapy and after third cycle
Poulos et al, 2001	Pain, mood disturbance, and QoL in patients with multiple myeloma	Quantitative/descriptive mailed survey	206	One data collection point
So et al, 2003	Fatigue and quality of life among chinese patients with hematologic malignancy after bone marrow transplant	Quantitative/descriptive Self-report questionnaires	157	One data collection point
Molassiotis et al, 1996a	Quality of life in long-term survivors of marrow transplantation: comparison with a matched group receiving maintenance chemotherapy.	Quantitative, Retrospective	164 - 91 long-term BMT survivors/73 maintenance chemotherapy	One data collection point

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Thain & Gibbon, 1996	An exploratory study of recipients' perceptions of BMT	Qualitative/exploratory	6 autologous & allogeneic HSCT	One data collection point
Persson & Hallberg, 2004	Lived experience of survivors of leukaemia or malignant lymphoma	Qualitative/phenomenology	18 in remission	One data collection point
Bertero, 1998	Transition to becoming a leukaemia patient: or putting up barriers which increase patient isolation	Qualitative/grounded theory Non-participant observation	4 patients & their nursing staff	Multiple data collection points
Persson et al, 1997	Survivors of acute leukaemia and highly malignant lymphoma- retrospective views of daily life problems during treatment and when in remission	Quantitative/descriptive Retrospective	54 in remission	One data collection point
Stephens, 2005	The lived experience post-autologous haematopoietic stem cell transplant (HSCT): A phenomenological study	Qualitative/phenomenology	5	One data collection point at least 6 months post-HSCT
Jones & Chapman, 2000	The lived experience of seven people treated with autologous BMT/PBSCT	Qualitative/phenomenology	7	One data collection point at least 12 months post-HSCT
Cohen & Ley, 2000	Bone marrow transplantation: The battle for hope in the face of fear	Qualitative/phenomenology	20 survivors – autologous HSCT	One data collection point (mean 16 months post-HSCT)

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Cooper & Powell, 1998	Technology and care in a bone marrow transplant unit: creating and assuaging vulnerability	Qualitative/descriptive	6	Multiple data collection points, pre- & post-HSCT
Shuster et al, 1996	Coping patterns among bone marrow transplant patients: a hermeneutical inquiry	Qualitative/ phenomenology	11	Multiple data collection points
Coon & Coleman, 2004a	Keep Moving: Patients with myeloma talk about exercise and fatigue.	Qualitative/naturalistic	21 (Enrolled in exercise arm of parent study)	Multiple data collection points.
Coon & Coleman, 2004b	Exercise decisions within the context of multiple myeloma, transplant and fatigue	Qualitative/descriptive	21 (Enrolled in exercise arm of parent study)	Multiple data collection points.
Pederson & Parran, 1999a	Pain in adult recipients of blood or marrow transplant	Qualitative/descriptive	20	Multiple data collection points.
Pederson & Parran, 1999b	Pain in adults and children undergoing peripheral blood stem cell or bone marrow transplant.	Quantitative/longitudinal/ descriptive	20 adults/20 children	Daily data collection (22 days)
David & Musgrave, 1996	Pain Assessment: A Pilot study in an Israeli BMT unit	Pilot study. Quantitative/descriptive	9	Multiple data collection points

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
McGuire et al, 1998	Acute oral pain and mucositis in bone marrow transplant and leukaemia patients: Data from a pilot study	Quantitative/descriptive	18	Multiple data collection points.
Borbasi et al, 2002	More than a sore mouth: patients experience of oral mucositis	Qualitative/phenomenology	6	Multiple data collection points.
Salvador, 2005	Factors influencing the incidence and severity of oral mucositis in patients undergoing autologous stem cell transplantation	Retrospective chart review. Quantitative/descriptive	140 myeloma & lymphoma	One data collection point
Molassiotis, 1999a	A correlational evaluation of tiredness and lack of energy in survivors of haematological malignancies.	Quantitative/descriptive Retrospective	164 -matched groups. 91 BMT survivors/73 maintenance chemotherapy	One data collection point 6 months post-HSCT or induction chemotherapy
El-Banna et al, 2004	Fatigue and depression in patients with lymphoma undergoing autologous peripheral blood stem cell transplantation	Quantitative/descriptive Self report questionnaires	27	Multiple data collection points.
Sitzia et al, 1997	Side-Effects of CHOP in the treatment of non-Hodgkin's lymphoma	Quantitative/descriptive. Self-report questionnaire	19	Each treatment cycle

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Molassiotis, 2003.	Anorexia and weight loss in long term survivors of haematological malignancies	Secondary data analysis	Study 1 (164) (91 BMT/73 conventional chemotherapy. Study 2 (28) unrelated donor BMT	Review of data from 2 previous studies
Larsen et al, 2004	Symptom occurrence, symptom intensity, and symptom distress in patients undergoing high-dose chemotherapy with stem-cell transplant	Quantitative/descriptive	43 mixed haem cancers and breast cancer	Multiple data collection points.
Molassiotis et al, 1996b	Psychological adaptation and symptom distress in BMT recipients	Quantitative/descriptive	26	Multiple data collection points.
Fife et al, 2000	Longitudinal study of adaptation to the stress of bone marrow transplantation.	Quantitative/descriptive	101	One data collection point at least 6 months post-BMT
Molassiotis, 1996	Late psychosocial effects of conditioning for BMT	Quantitative/descriptive	83	One data collection point
Molassiotis, 1997b	Psychosocial transitions in the long-term survivors of BMT	Quantitative/qualitative descriptive	91	Part of larger study One data collection point at least 6 months post-BMT

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of study	Sample Size	Data Collection Points
Individual Adaptation to Wellness and Illness				
Molassiotis et al, 1997	Perceived social support, family environment and psychosocial recovery in bmt long-term survivors	Quantitative/comparative	164 -91 BMT survivors/ 73 maintenance chemotherapy	One data collection point
Cohen et al, 2000	Spirituality and bone marrow transplantation: when faith is stronger than fear	Qualitative/phenomenology	20 (11 mixed haem cancers/9 breast)	One data collection point
Saleh & Brockopp, 2001a	Hope among patients with cancer hospitalized for bone marrow transplantation.	Qualitative/phenomenology	9	One data collection point
Bywater & Atkins, 2001	A study of factors influencing patients' decisions to undergo bone marrow transplantation from a sibling or matched related donor.	Qualitative/grounded theory	7	Multiple data collection points.

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Family Adaptation to Wellness and Illness				
Christopher, 2000	The experience of donating bone marrow to a relative	Qualitative/descriptive/ exploratory	12 (7 with living relatives, 5 had died)	One data collection point – mean 9 months since donation
Persson et al, 1998	Spouses' view during their partners' illness and treatment	Qualitative/phenomenology	9 – spouses had acute leukaemia /lymphoma	One data collection point
Rexilius et al, 2002	Therapeutic effects of massage therapy and healing touch on caregivers of patients undergoing autologous HSCT	Quantitative/quasi-experimental	36- 13 control/13 massage therapy/10 healing touch	Multiple data collection points.
Foxall & Gaston-Johansson, 1996	Burden and health outcomes of family caregivers of hospitalised BMT patients	Quantitative/descriptive Pilot study	24 caregivers	Multiple data collection points
Stetz et al, 1996	Needs and experiences of family caregivers during marrow transplantation	Qualitative/descriptive/ cross-sectional	19 adult family members	Multiple data collection points
Grimm et al, 2000	Caregiver responses and needs	Quantitative/descriptive/ longitudinal	43 caregivers	Multiple data collection points
Elmberger et al, 2002	Men with cancer	Qualitative/descriptive	8 with blood cancers & children living at home	One data collection point 1-7 years post-diagnosis

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Supporting and Non-Supporting Environments				
Gaskill et al, 1997	Exploring the everyday world of the patient in isolation	Qualitative/phenomenology	7	One data collection point
Grant et al, 2005	Discharge and unscheduled readmissions of adult patients undergoing hematopoietic stem cell transplantation: implications for developing nursing interventions	Quantitative/retrospective chart review	100	Review of records of patients transplanted in one year period
Mank & van der Lelie, 2003	Is there still an indication for nursing patients with prolonged neutropenia in protective isolation? An evidence-based nursing and medical study of 4 years experience for nursing patients with neutropenia without isolation	Literature review/patient data Quantitative/descriptive	81 patients 219 treatment episodes (AML) 44 with isolation and 37 without 97 patients HSCT 34 with isolation/ 63 without (97 episodes)	Longitudinal data collection
Coleman et al, 2002	Symptom management and successful outpatient transplantation for patients with multiple myeloma	Quantitative, record review. Descriptive, retrospective	87	Longitudinal analysis

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors/Title	Topic	Type of Study	Sample Size	Data Collection Points
Supporting and Non-Supporting Environments				
Herrmann et al, 1998	Clinical care for patients receiving autologous hematopoietic stem cell transplantation in the home setting	Pilot study Qualitative/quantitative Descriptive/cross-sectional	25 mixed haem cancers	Patient satisfaction one data collection point Finance and inpatient accommodation compared to each inpatient stay.
Schulmeister et al, 2005	Quality of life, quality of care, and patient satisfaction: perceptions of patients undergoing outpatient autologous stem cell transplantation	Descriptive Quantitative/qualitative	36 mixed haem & solid tumour	3 data collection points- before high dose chemotherapy, 4-6 weeks post-chemotherapy and 6 months post-chemotherapy.
Physiological Interventions				
So & Tai, 2005	Fatigue and Fatigue-Relieving Strategies Used by Hong Kong Chinese Patients After Hemopoietic Stem Cell Transplantation.	Quantitative, survey, self complete questionnaires	12	One data collection point
Johansson et al, 2005	Patients' experience of ambulatory self-administration of pamidronate in multiple myeloma	Qualitative/descriptive	24	Multiple data collection points.
Coleman et al, 2003	Feasibility of exercise for multiple myeloma	Quantitative/experimental	101 – 53 dry sterile gauze dressing, 48 moisture vapour permeable dressing	Multiple data collection points.

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Physiological Interventions				
Brandt et al, 1996	Comparison of central venous catheter dressings in BMT recipients	Quantitative/quasi-experimental	157	One data collection point
Molassiotis et al, 2005	Complementary and alternative medicine use in patients with haematological malignancies in Europe	Quantitative/ descriptive/cross-sectional	68 patients -12 European countries	One data collection point
Greco et al, 1996	Improvement of supportive nursing care in cancer patients autografted with bone marrow and mobilized peripheral blood haematopoietic progenitors	Quantitative/descriptive	39 lymphoma/ 1 breast	More than one data collection point but little information
Pederson & Parran, 2000	Opioid tapering in hematopoietic progenitor cell transplant recipients	Qualitative descriptive/ exploratory	45 – 33 adults/12 children	Multiple data collection points.
Parran & Pederson, 2002	Effects of an opioid taper algorithm in hematopoietic progenitor cell transplant recipients	Quasi-experimental	106 –77 adults/29 children	Multiple data collection points.

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Psychological Interventions				
Kim & Kim, 2005a	Effects of a relaxation breathing exercise on fatigue in haemopoietic stem cell transplantation patients	Quantitative/RCT	35 -18 breathing exercise, 17 control group	Pre- and post-test
Kim & Kim, 2005b	Effects of a Relaxation breathing exercise on anxiety, depression and leukocyte in hemopoietic stem cell transplantation patients	Quantitative/RCT	35 - 18 exercise, 17 control group (leukaemia or AA)	Pre- and post-test
Atkinson, 2005	Communicating news of patients' deaths to unrelated stem cell donors.	Quantitative/qualitative/ retrospective.	100	One data collection point
Smith et al, 2003	Outcomes of touch therapies during BMT	Quantitative/RCT	77 – 24 massage therapy, 28 therapeutic touch, 25 friendly visit	Record review and one data collection point for questionnaire
Bulsara et al, 2004	Haematological Cancer Patients: achieving a sense of empowerment by use of strategies to control illness.	Qualitative/phenomenology	12 mixed haem cancers & relatives	One data collection point
Bertero & Eriksson, 1996	Demanding interaction-given routines: An observational study on leukaemia patients and their nursing staff	Qualitative/grounded theory	4 patients/27 nursing staff	Multiple data collection points

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Psychological Interventions				
De Carvalho et al, 2000	Interpersonal needs expressed by patients during BMT	Qualitative/critical incident technique	23 conditioning phase, 19 transplant phase, 16 preparation for discharge phase (mixed haem cancers)	Multiple data collection points.
Ezzone et al, 1998	Music as an adjunct to antiemetic therapy	Quantitative/experimental	33- 17 control, 16 music intervention (mixed haem cancers)	Multiple data collection points
Professional Foundations for Practice				
Molassiotis, 1999b	Further evaluation of a scale to screen for risk of emotional difficulties in bone marrow transplant recipients	Quantitative/descriptive	40	Pre- & post-HSCT
Saleh & Brockopp, 2001b	Quality of life one year following BMT: psychometric evaluation of the QoLin BMT survivors tool.	Part of larger QoL study Quantitative/descriptive survey	70	One data collection point, at least one year post-BMT
Prior et al, 2000	Oncology nurses' experience of dimethyl sulfoxide odor.	Qualitative/descriptive	22 oncology nurses	One data collection point
Molassiotis & Haberman, 1996	Evaluation of burnout and job satisfaction in marrow transplant nurses	Quantitative/descriptive	40	One data collection point

Appendix 3 continued: Summary of Nursing Research in Haemato-Oncology 1996-March 2006

Authors	Title	Type of Study	Sample Size	Data Collection Points
Professional Foundations for Practice				
Young et al, 2002	Validation of the nursing diagnosis anxiety in adult patients undergoing BMT.	Quantitative/descriptive	32 patients, their significant others and their nurse	Multiple data collection points.
Goldberg & Musgrave, 1996	Informed consent: An Israeli BMT unit's perspective	Quantitative/pilot study	13 HSCT (haem cancers & solid tumours)	Pre- & post-HSCT
Courtens & Abu-Saad, 1998	Nursing diagnoses in patients with leukaemia	Qualitative/quantitative	15 nursing records, 7 oncology nurses	Record review and one data collection point
Colombo et al, 2005	Measurement of nursing care time of specific interventions on a hematology-oncology unit related to diagnostic categories	Quantitative, time & motion study/retrospective record review	5 nurses 29 admissions (records)	Patient observation Amount of nursing time related to category of treatment over one admission
McDonnell & Morris, 1997	Pilot study reports. An exploratory study of palliative care in BMT patients	Quantitative/qualitative exploratory/descriptive	52 – 33 nurses, 12 drs, 7 palliative care CNS	One data collection point
Pederson & Parran, 1997	BMT nurses' knowledge, beliefs and attitudes regarding pain management	Quantitative/descriptive/ exploratory	39 BMT nurses (20 paediatric, 19 adult)	One data collection point

Appendix 4: Round 1 Covering Letter and Questionnaire

Research Priorities in Haemato-Oncology Nursing

Identifying research priorities is one of the first steps in developing a research strategy. I am undertaking a study to identify research priorities in haemato-oncology nursing. It is anticipated that the results from this study will be used to direct future nursing research in the speciality. As an experienced practitioner your views are extremely valuable in this process and I would really appreciate your participation. The study will be undertaken in two phases:

Phase 1 – aims to identify the views of individual nurses in relation to research priorities in haemato-oncology nursing.

Phase 2 – aims to give respondents the chance to review and re-prioritise all responses from phase 1 to achieve a consensus

The attached questionnaire represents phase 1 of the study. I would be grateful if you would take a few minutes to complete the questionnaire and return it to me in the enclosed stamped addressed envelope by 20th February 2004. You can be assured that all your details will remain confidential and be viewed by myself only. No names or places of work will be identified in the final report. The results from this study will be published in the 2nd edition of Nursing in Haematological Oncology in 2005. I look forward to receiving your completed questionnaire.

Maggie Grundy

Maggie Grundy
Senior Lecturer

Research Priorities in Haemato-Oncology

Please answer the following questions about yourself and your place of work

1) **Place of Work (please circle most appropriate answer)**
    a) Haematology (non Blood/Marrow Transplant) in-patient area
    b) Haematology out-patient area
    c) Combined Haematology/Blood/Marrow Transplant unit
    d) Combined Haematology/other speciality area (please specify other speciality area)
    e) Blood/Marrow Transplant unit
    f) Other (please specify)

2) **Please specify your country of work**

3) **Nursing Role (please circle most appropriate answer)**

    a) Clinical Nurse
    b) Combined Clinical Nurse/Ward Manager
    c) Clinical Nurse Specialist
    d) Manager
    e) Researcher
    f) Educationalist
    g) Other (please specify)

4) **Number of years working in haemato-oncology (please circle most appropriate answer)**

    a) 1-5
    b) 6-10
    c) 11-15
    d) 16-20
    e) 21-25
    f) Over 25

5) **Age (please circle most appropriate answer)**
    a) 21-30
    b) 31-40
    c) 41-50
    d) 51-60
    e) Over 60

6) **Post registration qualifications (please circle highest qualification gained)**

a) Diploma
b) Degree
c) Masters
d) Doctorate

7) Do you have a specialist qualification in haematology or oncology nursing?

Yes/No

8) If your answer to question 7 was yes please specify your specialist qualification.

Research Priorities

In order of priority, please list the three most important questions or problems relating to haemato-oncology nursing that you consider should be researched.

1)
2)
3)

Second Round of Questionnaire

If you are willing to be involved in the 2nd phase of this study please print your name and contact details below:

Name:

Work Address:

Email Address:

Thank you for you time and cooperation in completing this questionnaire.

Appendix 5: Round 2 Covering Letter and Questionnaire

Dear

Research Priorities in Haemato-Oncology Nursing

At the beginning of the year you kindly completed a questionnaire on research priorities in haemato-oncology nursing and agreed to take part in the second round of the study. Identifying research priorities is one of the first steps in developing a research strategy. It is anticipated that the results from this study will be used to direct future nursing research in the speciality. As an experienced practitioner your views are extremely valuable in this process and I greatly appreciate your participation. Thank you very much for your input to the study so far. I hope you will continue to give your support to the study by completing the enclosed questionnaire.

The questionnaire is in two parts. Part One asks you some questions about yourself and your place of work. Part Two represents the research questions suggested by all respondents in the first round of the study. There were a lot of responses to the first round and many similar issues were identified. Any similar issues have been subsumed into one question. Some rewording of questions has also been undertaken in an effort to ensure clarity. However, care has been taken to retain the meaning of original statements.

The enclosed questionnaire will allow you prioritise the important questions for research in haemato-oncology nursing. I do hope you will find the time to complete the questionnaire. This is your chance to influence the research agenda. Please feel free to photocopy the questionnaire and pass it on to any colleagues working in haemato-oncology who may also be interested in participating in the study.

You can be assured that all your details will be remain confidential and be viewed by myself only. No names or places of work will be identified in the final report. The results from this study will be published in the 2nd edition of Nursing in Haematological Oncology in 2005.

The questionnaire should be returned to me in the enclosed SAE by 25th September 2004.

Yours sincerely

Maggie Grundy

Maggie Grundy
Senior Lecturer

Research Priorities in Haemato-Oncology

Part One: Guidelines for Completing the Questionnaire
This part of the questionnaire asks for some details about yourself and your place of work. It should only take a few minutes to complete.

1) Place of Work (please circle most appropriate answer)

a) Haematology (non Blood/Marrow Transplant) in-patient area
b) Haematology out-patient area
c) Combined Haematology/Blood/Marrow Transplant unit
d) Combined Haematology/other speciality area (please specify other speciality area)
e) Blood/Marrow Transplant unit
f) Other (please specify)

2) Please specify your country of work

3) Nursing Role (please circle most appropriate answer)

a) Clinical Nurse
b) Combined Clinical Nurse/Ward Manager
c) Clinical Nurse Specialist
d) Manager
e) Researcher
f) Educationalist
g) Other (please specify)

4) Number of years working in haemato-oncology (please circle most appropriate answer)

a) 1-5
b) 6-10
c) 11-15
d) 16-20
e) 21-25
f) Over 25

5) Age (please circle most appropriate answer)

a) 21-30
b) 31-40
c) 41-50
d) 51-60
e) Over 60

6) Post registration qualifications (please circle highest qualification gained)

a) Diploma
b) Degree
c) Masters
d) Doctorate

7) Do you have a specialist qualification in haematology or oncology nursing?
Yes/No

8) If your answer to question 7 was yes please specify your specialist qualification.

Further Questions
If you would be happy for me to contact you in the future in relation to this study please print your name and contact details below:

Name:

Work Address:

Email Address:

Research Priorities in Haemato-Oncology

Part Two: Guidelines for Completing the Questionnaire

This part of the questionnaire is split into 11 categories with a series of statements and questions in each category. You are asked to rate on a scale of 1-7 how important you perceive each statement or question to be for haemato-oncology research. You should circle the appropriate number on the rating scale to indicate your score. Scoring an item 1 would indicate a low priority and 7 a high priority. You can of course place your score anywhere between 1 and 7 depending on your perception of the importance of each item.

Example

	Rate each item in terms of importance for haemato-oncology nursing research
	Low High
Importance of the nursing role in clinical trials	1 2 3 4 5 6 [✓ 7]

In the example the item has been marked 7 for research importance and therefore perceived as very important for research.

At the end of each category you will also be asked to indicate the research statement/question you perceive to be the most important in that category by placing the number 1 by the appropriate item.

Please turn the page and complete the questionnaire.

Education

Rate each item in terms of importance for haemato-oncology nursing research

	Low						**High**
Educational needs of nurses at 3 levels novice, developing practice, expert	1	2	3	4	5	6	7
Access to haematological nurse education/courses	1	2	3	4	5	6	7
Educating general nurses of importance of haematology	1	2	3	4	5	6	7
How can high standards/levels of knowledge in cytotoxic administration be maintained?	1	2	3	4	5	6	7
How can chemotherapy training and administration be standardised throughout the UK?	1	2	3	4	5	6	7
Are safety precautions in the administration of cytotoxic drugs safe enough?	1	2	3	4	5	6	7
Is depth of knowledge of nurses administering chemotherapy sufficient?	1	2	3	4	5	6	7
What is nurses' awareness of drug related toxicity?	1	2	3	4	5	6	7
What is nurses' knowledge of neutropenic sepsis?	1	2	3	4	5	6	7
What is nurses' awareness of viral complications post BMT/PBSCT?	1	2	3	4	5	6	7
What is nurses' awareness of transfusion reactions?	1	2	3	4	5	6	7
Training on non clinical issues eg benefits?	1	2	3	4	5	6	7
What is the impact of specialist education?	1	2	3	4	5	6	7
Training of specialist nurses	1	2	3	4	5	6	7
Support/training of research nurses	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Service Delivery and Organisation of Care

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
What is the effect of staffing levels and skill mix on outcomes of care?	1	2	3	4	5	6	7
Does senior staff ratio ie sisters and above improve patient care?	1	2	3	4	5	6	7
Are staff shortages detrimental to practical/emotional support?	1	2	3	4	5	6	7
Recruitment and retention of all grades haematology/BMT nurses	1	2	3	4	5	6	7
How can staff be effectively rotated through a cancer network?	1	2	3	4	5	6	7
Are patient outcomes improved through multi-disciplinary team working?	1	2	3	4	5	6	7
What impact do different chemotherapy regimes have on nurse workload?	1	2	3	4	5	6	7
Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	1	2	3	4	5	6	7
Blood product replacement - are we over transfusing?	1	2	3	4	5	6	7
Is there a difference in care given in cancer centres and District General Hospitals?	1	2	3	4	5	6	7
Lack of specialist care in rural communities	1	2	3	4	5	6	7
Safety of care when haematology combined with another speciality	1	2	3	4	5	6	7
What are the benefits and limitations of increased outpatient and home care?	1	2	3	4	5	6	7
Improving services at home eg patient involvement and treatment options	1	2	3	4	5	6	7
Issues in shared care - is it effective?	1	2	3	4	5	6	7

Service Delivery and Organisation of Care

Rate each item in terms of importance for haemato-oncology nursing research

	Low						**High**
How can continuity of care be improved?	1	2	3	4	5	6	7
Does collaboration exist in haematology between drs and nurses?	1	2	3	4	5	6	7
Should haematology be separate from oncology?	1	2	3	4	5	6	7
When is appropriate time to refer to Macmillan services?	1	2	3	4	5	6	7
Do we overuse blood tests? Especially in lymphoma	1	2	3	4	5	6	7
Impact of the inevitable reduction of blood donors for haematology patients	1	2	3	4	5	6	7
Are palliative care needs being addressed?	1	2	3	4	5	6	7
Transition from curative to palliative care & treatment	1	2	3	4	5	6	7
How can better links with palliative care services be facilitated?	1	2	3	4	5	6	7
Consistency of practice between palliative care and haematology	1	2	3	4	5	6	7
Palliative care - when should it be initiated?	1	2	3	4	5	6	7
Gaining enthusiasm from health professionals for clinical trials/research	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Effects of Role on Nurses' Health and Support Needs

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Psychological effects on health care professionals working in BMT/haematology	1	2	3	4	5	6	7
Does BMT burnout in nurses exist today?	1	2	3	4	5	6	7
What are the psychological support needs of nurses & other health care professionals?	1	2	3	4	5	6	7
Staff support and counselling	1	2	3	4	5	6	7
Availability of training and support and effects on stress development	1	2	3	4	5	6	7
Is effective clinical supervision available to nurses in haemato-oncology?	1	2	3	4	5	6	7
How staff feel about the workplace	1	2	3	4	5	6	7
Long term health risks of nurses exposed to chemotherapy/antibiotics	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Communication/Patient Information and Education

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Is time available to identify patient concerns?	1	2	3	4	5	6	7
Effect of communication good/bad on patients	1	2	3	4	5	6	7
Breaking bad news. Who does the patient prefer nurses or drs?	1	2	3	4	5	6	7
Nurses' reactions to dealing with emotional questions	1	2	3	4	5	6	7
Timeliness/quality/amount of information at diagnosis and relapse	1	2	3	4	5	6	7
Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	1	2	3	4	5	6	7
Information giving and patient empowerment	1	2	3	4	5	6	7
What information do patients require on specific aspects of care?	1	2	3	4	5	6	7
Provision of information for children of adults with a haematological cancer	1	2	3	4	5	6	7
Patients and carers education on physical aspects of care	1	2	3	4	5	6	7
Education and pre-assessment of patients having chemotherapy	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Ethical Decision Making

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
When to actively treat and when to withdraw treatment	1	2	3	4	5	6	7
Making decision when active treatment ends and palliative treatment begins	1	2	3	4	5	6	7
Appropriate use of blood transfusion in haematological palliative care	1	2	3	4	5	6	7
Ethical issues of treatment of the elderly	1	2	3	4	5	6	7
Does the patient receive sufficient information to provide informed patient consent?	1	2	3	4	5	6	7
How can informed consent be ensured if the patient is incapacitated?	1	2	3	4	5	6	7
How do patients make decisions about clinical trials at diagnosis?	1	2	3	4	5	6	7
What is the nurses' advocacy role for haemato-oncology patients?	1	2	3	4	5	6	7
How can patients have more autonomy?	1	2	3	4	5	6	7
How can end of journey decision making with patients be improved?	1	2	3	4	5	6	7
Ethical issues related to DNA technologies	1	2	3	4	5	6	7
Truth telling in BMT/PBSCT	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Utilising Knowledge and Developing the Evidence Base for Practice	**Rate each item in terms of importance for haemato-oncology nursing research**						
	Low						**High**
Department of Health Improving Outcomes Guidelines are they making a difference?	1	2	3	4	5	6	7
National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	1	2	3	4	5	6	7
Develop evidence base for optimal care/ use/ problem solving of central venous catheters including reducing infection/preventing thrombosis	1	2	3	4	5	6	7
Implementing an effective audit tool to monitor hickman line care	1	2	3	4	5	6	7
Clear guidelines on mucositis management	1	2	3	4	5	6	7
Oral care protocol - what's best?	1	2	3	4	5	6	7
What are the most effective mouthwashes during chemotherapy?	1	2	3	4	5	6	7
What is best practice in protective isolation care? Is there a best practice?	1	2	3	4	5	6	7
Development of evidence base for optimal control of nausea & vomiting	1	2	3	4	5	6	7
What is best practice for nursing management of day care patients?	1	2	3	4	5	6	7
Prevention of reactions to blood/platelet transfusions	1	2	3	4	5	6	7
What nursing theory should underpin haematology nursing practice?	1	2	3	4	5	6	7
How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	1	2	3	4	5	6	7
Treatment safety including blood	1	2	3	4	5	6	7

Utilising Knowledge and Developing the Evidence Base for Practice

Rate each item in terms of importance for haemato-oncology nursing research

	Low						**High**
Safety issues related to nebulised pentamidine administration	1	2	3	4	5	6	7
How can clinical research be implemented into practice?	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Nursing Interventions and Care

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
How can prevention of infection measures be improved?	1	2	3	4	5	6	7
Management and care of neutropenic patients	1	2	3	4	5	6	7
Long term follow up/rehabilitation for patients with haematological cancers	1	2	3	4	5	6	7
Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	1	2	3	4	5	6	7
Are antimicrobial diets/clean food regimes beneficial in neutropenia?	1	2	3	4	5	6	7
Venous access assessment in ensuring correct device used	1	2	3	4	5	6	7
Central venous catheters - do risks outweigh the benefits?	1	2	3	4	5	6	7
How can needs of older inpatients with myeloma & CLL be best met?	1	2	3	4	5	6	7
Are fertility issues addressed?	1	2	3	4	5	6	7
Pre- BMT care	1	2	3	4	5	6	7
Immediate care post BMT	1	2	3	4	5	6	7
Exercise and fitness during and after transplant	1	2	3	4	5	6	7
Dealing with relatively young patients	1	2	3	4	5	6	7
What is the role of alternative therapies?	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Symptom Management

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Disease and treatment related fatigue	1	2	3	4	5	6	7
Control of gastric symptoms during allogeneic BMT	1	2	3	4	5	6	7
Skin care post allogeneic BMT	1	2	3	4	5	6	7
Management of veno-occlusive crisis	1	2	3	4	5	6	7
Management of GVHD treatment complications	1	2	3	4	5	6	7
How can the side-effects of chemotherapy be reduced?	1	2	3	4	5	6	7
Elimination problems due to treatment	1	2	3	4	5	6	7
Alopecia	1	2	3	4	5	6	7
Is pain control during bone marrow biopsies effective?	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Psychosocial Wellbeing and Support

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Are sexuality issues addressed?	1	2	3	4	5	6	7
What is the extent/impact of sexual dysfunction?	1	2	3	4	5	6	7
Spirituality	1	2	3	4	5	6	7
Cultural Issues	1	2	3	4	5	6	7
Quality of life - What does it really mean to the patient?	1	2	3	4	5	6	7
Long term survival anxiety when returning to clinic for follow up	1	2	3	4	5	6	7
What are the effects of surviving long term?	1	2	3	4	5	6	7
What are the short and long term psychological effects of isolation?	1	2	3	4	5	6	7
What are the psychosocial support needs of patients with haematological cancers and their families?	1	2	3	4	5	6	7
How could nurses improve support for patients?	1	2	3	4	5	6	7
What are the psychological needs of the older haematology patient?	1	2	3	4	5	6	7
Psychological effects of haematological cancers	1	2	3	4	5	6	7
Should specific criteria be used for pre-transplant psychological assessment?	1	2	3	4	5	6	7
Measure psychological interventions for haematology patients	1	2	3	4	5	6	7
What short and long term psychosocial coping strategies do patients use?	1	2	3	4	5	6	7

Psychosocial Wellbeing and Support

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Mental illness in BMT	1	2	3	4	5	6	7
What is the correlation between myelosuppression and depression for the isolated patient?	1	2	3	4	5	6	7
How do patients cope with fatigue?	1	2	3	4	5	6	7
What difficulties do patients have with compliance in taking long term medication?	1	2	3	4	5	6	7
Role of hypnotherapy & psychoneuroimmunology	1	2	3	4	5	6	7
Ongoing psychological care from hospital to home	1	2	3	4	5	6	7
Should a psychologist/counsellor be involved at ward level for patients & relatives?	1	2	3	4	5	6	7
What is the value of counselling for BMT patients pre & post transplant?	1	2	3	4	5	6	7
What is the psychological impact of BMT?	1	2	3	4	5	6	7
What effect do haematological cancers have on mood/personality?	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Patient and Family Experience

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
What is the lived experience of receiving diagnosis/achieving remission?	1	2	3	4	5	6	7
Patient view of the meaning of a cancer diagnosis	1	2	3	4	5	6	7
How can patient experience of diagnosis and follow up be improved?	1	2	3	4	5	6	7
Patient experience of current care	1	2	3	4	5	6	7
Lack of psychosocial care for patients and families	1	2	3	4	5	6	7
Haematology patients' views on admission to an intensive care unit	1	2	3	4	5	6	7
Patients views of where they are treated	1	2	3	4	5	6	7
Experiences of patients with failed stem cell harvest	1	2	3	4	5	6	7
Patient experiences of symptom control	1	2	3	4	5	6	7
Patient experiences of hospitalisation	1	2	3	4	5	6	7
What do patients expect/require from nurses?	1	2	3	4	5	6	7
How important to patients is access to a CNS?	1	2	3	4	5	6	7
How do patients perceive the role of nurse specialist?	1	2	3	4	5	6	7
Effect of low staff morale and staffing on experiences of isolated patient	1	2	3	4	5	6	7
What do patients perceive as the benefits of having a bone marrow transplant?	1	2	3	4	5	6	7

Patient and Family Experience

Rate each item in terms of importance for haemato-oncology nursing research

	Low						**High**
Impact of myeloproliferative disorders on lives	1	2	3	4	5	6	7
Impact of haematological cancer on family dynamics/relationships	1	2	3	4	5	6	7
Family support for patients having BMT/lengthy chemotherapy	1	2	3	4	5	6	7
Psychological effects of intensive treatment on patients & families	1	2	3	4	5	6	7
Psychological effects of relapse for the patient & family	1	2	3	4	5	6	7
What effect does a palliative prognosis have on the patient?	1	2	3	4	5	6	7
Support of carers	1	2	3	4	5	6	7
Relatives role in nursing an oncology patient	1	2	3	4	5	6	7
Spouse/significant others experiences and supportive role	1	2	3	4	5	6	7
Effects of illness on family especially spouse/partner?	1	2	3	4	5	6	7
What are the psychological issues for sibling donors?	1	2	3	4	5	6	7
What is the donor experience?	1	2	3	4	5	6	7
Nurses' role in supporting the donor	1	2	3	4	5	6	7
What are the short and long term side-effects of GCSF on donors?	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Nurses' Role

Rate each item in terms of importance for haemato-oncology nursing research

	Low						High
Should follow up of haematology patients be nurse led?	1	2	3	4	5	6	7
How effective/successful are nurse led services?	1	2	3	4	5	6	7
Development of extended role for nurses in haemato-oncology	1	2	3	4	5	6	7
Nurses' role in care of haemato-oncology patient in BMT workup	1	2	3	4	5	6	7
Nurses undertaking bone marrow aspiration - will it improve patient experience?	1	2	3	4	5	6	7
Do haematology patients with malignant disease get sufficient specialist nurse support?	1	2	3	4	5	6	7
What access do patients in the UK have to a CNS?	1	2	3	4	5	6	7
How effective is the CNS role in haemato-oncology?	1	2	3	4	5	6	7
Role of the nurse consultant in haemato-oncology	1	2	3	4	5	6	7
Career development for haemato-oncology nurses	1	2	3	4	5	6	7
Critical care skills are they an essential requirement for haematology/BMT nurses?	1	2	3	4	5	6	7
Minimum skills/requirements for UK haematology nurses/researchers/managers	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

If you think there are important research priorities that have been omitted from this questionnaire please list these below.

Thank you for you time and cooperation in completing this questionnaire

Please return your completed questionnaire in the enclosed SAE by 25th September 2004

Appendix 6: Round 3 Covering Letter and Questionnaire

13th June 2005

Dear

Research Priorities in Haemato-Oncology Nursing

Last year you participated in a Delphi study of research priorities in haemato-oncology nursing which aimed to gain agreement from practising nurses on priority topics. Thank you very much for your taking the time to contribute to this study. The response to the 2nd round was excellent and your participation is greatly appreciated.

Results from the second round of the study were ranked in order of priority and show that many of the topics have tied places. Many other topics are clustered closely together suggesting that agreement may not have been reached. I have enclosed the list of topics ranked in order of priority for your information.

For the above reasons I have decided to undertake a 3rd round of the study in an attempt to identify the most important research topics for nurses working in haemato-oncology. Identifying these topics is important as it will allow us to develop structured programmes of research.

Once again I would really appreciate your help with this. I enclose a further questionnaire and would be grateful if you could spare the time to complete this and return it to me in the enclosed stamped addressed envelope. Your views are important. The greater the number of responses I receive from practising nurses the more likely I am to be able to identify the research topics that really matter.

The questionnaire is in two parts. Part One asks you some questions about yourself and your place of work. Part Two represents the research questions suggested by all respondents in the first round of the study. These questions are divided into 11 categories and you are asked to identify your top 3 priorities in each category allowing you to prioritise important research topics. The priority ranking attributed to each topic in the second round of the study is also included here.

I do hope you will find the time to complete this questionnaire. This is your chance to influence the research agenda. Please feel free to photocopy the questionnaire and pass it on to any of your colleagues who may also be interested in participating in the study.

You can be assured that all your details will remain confidential and be viewed by myself only. No names or places of work will be identified in the final report.

Results from the first 2 rounds of the study have been written up and will be published in the 2nd edition of Nursing in Haematological Oncology in 2006.

Please return the questionnaire to me in the enclosed SAE by 12th August 2005. I look forward to hearing from you.

With best wishes
Yours sincerely

Maggie Grundy

Maggie Grundy
Senior Lecturer

Research Priorities in Haemato-Oncology

Part Two: Guidelines for Completing the Questionnaire

This part of the questionnaire is split into 11 categories with a series of statements and questions in each category. You are asked to identify the 3 topics you consider to be the highest priority for research in each category in the left hand column. The second round rank of each item is indicated in the second column.

Example

Priority No.	Rank	Research Topics
Indicate the 3 topics you consider to be the highest research priorities for this category priorities in this column by using the numbers 1-3	This column demonstrates the second round rank for each item	Research priorities identified in previous rounds of the study are listed in this column.

Please turn the page and complete the questionnaire.

Rank	Education	Priority No
3	What is nurses' knowledge of neutropenic sepsis?	
7	Access to haematological nurse education/courses	
10	How can chemotherapy training and administration be standardised throughout the UK?	
17	What is nurses' awareness of transfusion reactions?	
21	How can high standards/levels of knowledge in cytotoxic administration be maintained?	
24	Are safety precautions in the administration of cytotoxic drugs safe enough?	
57	Is depth of knowledge of nurses administering chemotherapy sufficient?	
64	What is nurses' awareness of drug related toxicity?	
80	Educational needs of nurses at 3 levels novice, developing practice, expert	
134	Training of specialist nurses	
142	What is nurses' awareness of viral complications post BMT/PBSCT?	
156	Educating general nurses of importance of haematology	
156	What is the impact of specialist education?	
169	Support/training of research nurses	
177	Training on non clinical issues eg benefits?	

Rank	Service Delivery and Organisation of Care	Priority No
4	Are staff shortages detrimental to practical/emotional support?	
21	What is the effect of staffing levels and skill mix on outcomes of care?	
33	Transition from curative to palliative care & treatment	
52	What are the benefits and limitations of increased outpatient and home care?	
64	Are patient outcomes improved through multi-disciplinary team working?	
64	Are palliative care needs being addressed?	
72	Safety of care when haematology combined with another speciality	
80	Palliative care - when should it be initiated?	
93	Improving services at home eg patient involvement and treatment options	
93	How can continuity of care be improved?	
100	What impact do different chemotherapy regimes have on nurse workload?	
100	Consistency of practice between palliative care and haematology	
112	Is there a difference in care given in cancer centres and District General Hospitals?	
117	Recruitment and retention of all grades haematology/BMT nurses	
117	Blood product replacement - are we over transfusing?	
117	How can better links with palliative care services be facilitated?	
134	Does senior staff ratio ie sisters and above improve patient care?	
145	Impact of the inevitable reduction of blood donors for haematology patients	
156	Does collaboration exist in haematology between drs and nurses?	
161	Lack of specialist care in rural communities	
162	Issues in shared care - is it effective?	
168	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	
170	Should haematology be separate from oncology?	
171	Gaining enthusiasm from health professionals for clinical trials/research	
173	When is appropriate time to refer to Macmillan services?	
175	How can staff be effectively rotated through a cancer network?	
176	Do we overuse blood tests? Especially in lymphoma	

Rank	Effects of Role on Nurses' Health and Support Needs	Priority No
2	Long term health risks of nurses exposed to chemotherapy/antibiotics	
57	Psychological effects on health care professionals working in BMT/haematology	
64	What are the psychological support needs of nurses & other health care professionals?	
134	Staff support and counselling	
134	Is effective clinical supervision available to nurses in haemato-oncology?	
148	Does BMT burnout in nurses exist today?	
159	How staff feel about the workplace	
164	Availability of training and support and effects on stress development	

Rank	Communication/Patient Information and Education	Priority No
1	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	
17	Provision of information for children of adults with a haematological cancer	
17	Effect of communication good/bad on patients	
28	Timeliness/quality/amount of information at diagnosis and relapse	
33	Education and pre-assessment of patients having chemotherapy	
38	Information giving and patient empowerment	
48	What information do patients require on specific aspects of care?	
72	Breaking bad news. Who does the patient prefer nurses or drs?	
85	Is time available to identify patient concerns?	
93	Nurses' reactions to dealing with emotional questions	
128	Patients and carers education on physical aspects of care	

Rank	Ethical Decision Making	Priority No
6	Making decision when active treatment ends and palliative treatment begins	
10	When to actively treat and when to withdraw treatment	
43	Does the patient receive sufficient information to provide informed patient consent?	
64	Truth telling in BMT/PBSCT	
72	How can end of journey decision making with patients be improved?	
72	What is the nurses' advocacy role for haemato-oncology patients?	
80	Appropriate use of blood transfusion in haematological palliative care	
93	How do patients make decisions about clinical trials at diagnosis?	
112	Ethical issues of treatment of the elderly	
140	How can informed consent be ensured if the patient is incapacitated?	
142	How can patients have more autonomy?	
171	Ethical issues related to DNA technologies	

Rank	Utilising Knowledge and Developing the Evidence Base for Practice	Priority No
28	Clear guidelines on mucositis management	
28	What is best practice in protective isolation care? Is there a best practice?	
33	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	
38	Develop evidence base for optimal care/ use/ problem solving of central venous catheters including reducing infection/preventing thrombosis	
38	Oral care protocol - what's best?	
48	How can clinical research be implemented into practice?	
72	Development of evidence base for optimal control of nausea & vomiting	
88	Treatment safety including blood	
93	Implementing an effective audit tool to monitor hickman line care	
112	What are the most effective mouthwashes during chemotherapy?	
112	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	
140	Safety issues related to nebulised pentamidine administration	
140	What is best practice for nursing management of day care patients?	
142	What nursing theory should underpin haematology nursing practice?	
164	Prevention of reactions to blood/platelet transfusions	
164	Department of Health Improving Outcomes Guidelines are they making a difference?	

Rank	Nursing Interventions and Care	Priority No
10	Management and care of neutropenic patients	
21	How can prevention of infection measures be improved?	
48	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	
48	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	
76	Long term follow up/rehabilitation for patients with haematological cancers	
88	How can needs of older inpatients with myeloma & CLL be best met?	
88	Are fertility issues addressed?	
100	Venous access assessment in ensuring correct device used	
123	Immediate care post BMT	
123	Dealing with relatively young patients	
131	Central venous catheters - do risks outweigh the benefits?	
142	Pre- BMT care	
156	What is the role of alternative therapies?	
166	Exercise and fitness during and after transplant	

Rank	Symptom Management	Priority No
21	How can the side-effects of chemotherapy be reduced?	
38	Disease and treatment related fatigue	
52	Management of GVHD treatment complications	
93	Control of gastric symptoms during allogeneic BMT	
107	Is pain control during bone marrow biopsies effective?	
123	Skin care post allogeneic BMT	
128	Management of veno-occlusive crisis	
145	Elimination problems due to treatment	
174	Alopecia	

Rank	Psychosocial Wellbeing and Support	Priority No
13	Quality of life - What does it really mean to the patient?	
17	How could nurses improve support for patients?	
28	What are the psychosocial support needs of patients with haematological cancers and their families?	
38	Long term survival anxiety when returning to clinic for follow up	
43	Psychological effects of haematological cancers	
43	What is the psychological impact of BMT?	
52	What is the value of counselling for BMT patients pre & post transplant?	
57	What are the effects of surviving long term?	
57	Should a psychologist/counsellor be involved at ward level for patients & relatives?	
72	What are the psychological needs of the older haematology patient?	
76	What are the short and long term psychological effects of isolation?	
100	What effect do haematological cancers have on mood/personality?	
100	What short and long term psychosocial coping strategies do patients use?	
100	What is the correlation between myelosuppression and depression for the isolated patient?	
107	Are sexuality issues addressed?	
117	What is the extent/impact of sexual dysfunction?	
123	Should specific criteria be used for pre-transplant psychological assessment?	
134	How do patients cope with fatigue?	
148	Measure psychological interventions for haematology patients	
151	Spirituality	
153	Ongoing psychological care from hospital to home	
159	What difficulties do patients have with compliance in taking long term medication?	
162	Cultural Issues	
166	Mental illness in BMT	
178	Role of hypnotherapy & psychoneuroimmunology	

Rank	Patient and Family Experience	Priority No
4	What do patients expect/require from nurses?	
10	Psychological effects of relapse for the patient & family	
24	Effect of low staff morale and staffing on experiences of isolated patient	
38	What effect does a palliative prognosis have on the patient?	
43	Patient experiences of symptom control	
48	How important to patients is access to a CNS?	
52	Impact of haematological cancer on family dynamics/relationships	
57	How can patient experience of diagnosis and follow up be improved?	
57	Effects of illness on family especially spouse/partner?	
64	Psychological effects of intensive treatment on patients & families	
64	Spouse/significant others experiences and supportive role	
80	What is the lived experience of receiving diagnosis/achieving remission?	
80	Patients views of where they are treated	
80	What are the short and long term side-effects of GCSF on donors?	
88	Patient experience of current care	
100	Family support for patients having BMT/lengthy chemotherapy	
100	Patient experiences of hospitalisation	
107	Patient view of the meaning of a cancer diagnosis	
107	How do patients perceive the role of nurse specialist?	
112	What are the psychological issues for sibling donors?	
117	Lack of psychosocial care for patients and families	
123	Experiences of patients with failed stem cell harvest	
128	Relatives role in nursing an oncology patient	
128	Impact of myeloproliferative disorders on lives	
134	Support of carers	
148	What is the donor experience?	
148	Nurses' role in supporting the donor	
151	What do patients perceive as the benefits of having a bone marrow transplant?	
153	Haematology patients' views on admission to an intensive care unit	

Rank	Nurses' Role	Priority No
10	How effective/successful are nurse led services?	
13	Critical care skills are they an essential requirement for haematology/BMT nurses?	
17	Minimum skills/requirements for UK haematology nurses/researchers/managers	
28	Development of extended role for nurses in haemato-oncology	
28	How effective is the CNS role in haemato-oncology?	
38	Career development for haemato-oncology nurses	
64	Do haematology patients with malignant disease get sufficient specialist nurse support?	
72	Role of the nurse consultant in haemato-oncology	
85	Should follow up of haematology patients be nurse led?	
85	Nurses' role in care of haemato-oncology patient in BMT workup	
107	Nurses undertaking bone marrow aspiration - will it improve patient experience?	
123	What access do patients in the UK have to a CNS?	

Appendix 7: Ethical Approval Letter

NHS GRAMPIAN
AND
UNIVERSITY OF ABERDEEN

GRAMPIAN RESEARCH ETHICS COMMITTEE

Chairmen
Committee One
Dr John Dean
Consultant
Department of Medical Genetics
Medical School
Foresterhill
Aberdeen
AB25 2ZD

Tel: (01224) 552120
Fax: (01224) 559390

Committee Two
Professor Nigel Webster
Professor of Anaesthesia & Intensive Care
Institute of Medical Sciences
Foresterhill
Aberdeen
AB25 2ZD

Tel: (01224) 555167
Fax: (01224) 555766

Clerk to the Committee

Dept of Public Health
NHS Grampian
Summerfield House
2 Eday Road
ABERDEEN, AB15 6RE

Tel: (01224) 558503
Fax: (01224) 558609

27th April 2004

REC Ref:

Dr Maggie Grundy
Senior Lecturer School of Nursing & Midwifery
Garthdee C113
Garthdee Road
Aberdeen
AB10 7QG

Dear Dr Grundy

Re: The Delphi Study

Thank you for your recent correspondance regarding the above named strudy. I am pleased to confirm that ethical approval is not required from the Grampian Research Ethics Committee as the project you describe in your email is regarded as an audit in order to improve clinical service.

We will retain a copy of this letter and your email on file.

Thank you for bringing this study to the committee's attemntion.

Yours sincerely

K.m. Macleod.

Mrs Kellie MacLeod
Manager
Grampian Research Ethics Committees

Cc: Research & Development Department. NHS Grampian

Your application has been given a unique reference number, please use it on all correspondence with the LREC.

Appendix 8: Pilot Study Questionnaire

Education	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Educational needs of nurses at 3 levels novice, developing practice, expert	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Access to haematological nurse education/courses	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Educating general nurses of importance of haematology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can high standards/levels of knowledge in cytotoxic administration be maintained?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can chemotherapy training and administration be standardised throughout the UK?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are safety precautions in the administration of cytotoxic drugs safe enough?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Is depth of knowledge of nurses administering chemotherapy sufficient?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is nurses' awareness of drug related toxicity?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is nurses' knowledge of neutropenic sepsis?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is nurses' awareness of viral complications post BMT/PBSCT?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is nurses' awareness of transfusion reactions?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Training on non clinical issues eg benefits?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the impact of specialist education?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Training of specialist nurses	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Support/training of research nurses	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Service Delivery and Organisation of Care	**How importance is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
What is the effect of staffing levels and skill mix on outcomes of care?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Does senior staff ratio ie sisters and above improve patient care?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are staff shortages detrimental to practical/emotional support?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Recruitment and retention of all grades haematology/BMT nurses	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can staff be effectively rotated through a cancer network?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are patient outcomes improved through multi-disciplinary team working?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What impact do different chemotherapy regimes have on nurse workload?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Impact of NICE guidelines on nursing hours	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Blood product replacement - are we over transfusing?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Is there a difference in care given in cancer centres and DGH's?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Lack of specialist care in rural communities	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Safety of care when haematology combined with another speciality	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the benefits and limitations of increased outpatient and home care?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Improving services at home eg patient involvement and treatment options	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Issues in shared care - is it effective?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Service Delivery and Organisation of Care

	How important is this topic for haemato-oncology nursing research?							**How important is this topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
How can continuity of care be improved?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Does collaboration exist in haematology between drs and nurses?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Should haematology be separate from oncology?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
When is appropriate time to refer to Macmillan services?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Do we overuse blood tests? Especially in lymphoma	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Impact of the inevitable reduction of blood donors for haematology patients	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are palliative care needs being addressed?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Transition from curative to palliative care & treatment	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can better links with palliative care services be facilitated?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Consistency of practice between palliative care and haematology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Palliative care - when should it be initiated?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Gaining enthusiasm from health professionals for clinical trials/research	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Effects of Role on Nurses' Health and Support Needs	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Psychological effects on health care professionals working in BMT/haematology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Does BMT burnout in nurses exist today?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the psychological support needs of nurses & other health care professionals?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Staff support and counselling	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Availability of training and support and effects on stress development	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Is effective clinical supervision available to nurses in haemato-oncology?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How staff feel about the workplace	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Long term health risks of nurses exposed to chemotherapy/antibiotics	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Communication/Patient Information and Education

	How important is each topic for haemato-oncology nursing research?							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Is time available to identify patient concerns?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Effect of communication good/bad on patients	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Breaking bad news. Who does the patient prefer nurses or drs?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Nurses' reactions to dealing with emotional questions	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Timeliness/quality/amount of information at diagnosis and relapse	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Information giving and patient empowerment	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What information do patients require on specific aspects of care?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Provision of information for children of adults with a haematological cancer	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patients and carers education on physical aspects of care	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Education and pre-assessment of patients having chemotherapy	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Ethical Decision Making

	How important is each topic for haemato-oncology nursing research?							How important is each topic for haemato-oncology nurse education?						
	Low						High	Low						High
When to actively treat and when to withdraw treatment	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Making decision when active treatment ends and palliative treatment begins	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Appropriate use of blood transfusion in haematological palliative care	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Ethical issues of treatment of the elderly	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Does the patient receive sufficient information to provide informed patient consent?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can informed consent be ensured if the patient is incapacitated?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How do patients make decisions about clinical trials at diagnosis?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the nurses' advocacy role for haemato-oncology patients?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can patients have more autonomy?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can end of journey decision making with patients be improved?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Ethical issues related to DNA technologies	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Truth telling in BMT/PBSCT	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Utilising Knowledge and Developing the Evidence Base for Practice	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
DOH Improving Outcomes Guidelines are they making a difference?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
National guidelines/standards of care for central venous catheters including dressings, cleaning & flushing	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Develop evidence base for optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Implementing an effective audit tool to monitor hickman line care	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Clear guidelines on mucositis management	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Oral care protocol - what's best?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the most effective mouthwashes during chemotherapy?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is best practice in protective isolation care? Is there a best practice?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Development of evidence base for optimal control of nausea & vomiting	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is best practice for nursing management of day care patients?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Prevention of reactions to blood/platelet transfusions	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What nursing theory should underpin haematology nursing practice?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Treatment safety including blood	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Safety issues related to nebulised pentamidine administration	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Utilising Knowledge and Developing the Evidence Base for Practice	**How important is each topic for haemato-oncology nursing research?**	**How important is each topic for haemato-oncology nurse education?**
	Low **High**	**Low** **High**
Safety issues related to nebulised pentamidine administration	1 2 3 4 5 6 7	1 2 3 4 5 6 7
How can clinical research be implemented into practice?	1 2 3 4 5 6 7	1 2 3 4 5 6 7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Nursing Interventions and Care	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
How can prevention of infection measures be improved?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Management and care of neutropenic patients	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Long term follow up/rehabilitation for patients with haematological cancers	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are antimicrobial diets/clean food regimes beneficial in neutropenia?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Venous access assessment ensuring correct device used	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Central venous catheters - do risks outweigh the benefits?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can needs of older inpatients with myeloma & CLL be best met?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Are fertility issues addressed?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Pre- BMT care	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Immediate care post BMT	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Exercise and fitness during and after transplant	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Dealing with relatively young patients	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the role of alternative therapies?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Symptom Management	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						
Disease and treatment related fatigue	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Control of gastric symptoms during allogeneic BMT	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Skin care post allogeneic BMT	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Management of veno-occlusive crisis	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Management of GVHD treatment complications	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can the side-effects of chemotherapy be reduced?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Elimination problems due to treatment	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Does cold capping work?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Is pain control during bone marrow biopsies effective?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Psychosocial Wellbeing and Support	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Are sexuality issues addressed?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the extent/impact of sexual dysfunction?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Spirituality	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Quality of life - What does it really mean to the patient?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Long term survival anxiety when returning to clinic for follow up	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the effects of surviving long term?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the short and long term psychological effects of isolation?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the psychosocial support needs of patients with haematological cancers and their families?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How could nurses improve support for patients?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the psychological needs of the older haematology patient?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Psychological effects of haematological cancers	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Should specific criteria be used for pre-transplant psychological assessment?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Measure psychological interventions for haematology patients	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What short and long term psychosocial coping strategies do patients use?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Mental illness in BMT	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Psychosocial Wellbeing and Support	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
What is the correlation between myelosuppression and depression for the isolated patient?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How do patients cope with fatigue?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What difficulties do patients have with compliance in taking long term medication?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Role of hypnotherapy & psychoneuroimmunology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Ongoing psychological care from hospital to home	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Should a psychologist/counsellor be involved at ward level for patients & relatives?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the value of counselling for BMT patients pre & post transplant?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the psychological impact of BMT?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What effect do haematological cancers have on mood/personality?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Patient and Family Experience	**How important is each topic for haemato-oncology nursing research?**							**How important is each topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
What is the lived experience of receiving diagnosis/achieving remission?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patient view of the meaning of a cancer diagnosis	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How can patient experience of diagnosis and follow up be improved?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patient experience of current care	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Lack of psychosocial care for patients and families	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Haematology patients' views on ICU admission	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patients views of where they are treated	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Experiences of patients with failed stem cell harvest	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patient experiences of symptom control	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Patient experiences of hospitalisation	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What do patients expect/require from nurses?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How important to patients is access to a CNS?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How do patients perceive the role of nurse specialist?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Effect of low staff morale and staffing on experiences of isolated patient	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What do patients perceive as the benefits of having a bone marrow transplant?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Patient and Family Experience	**How important is this topic for haemato-oncology nursing research?**							**How important is this topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Impact of myeloproliferative disorders on lives	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Impact of haematological cancer on family dynamics/relationships	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Family support for patients having BMT/lengthy chemotherapy	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Psychological effects of intensive treatment on patients & families	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Psychological effects of relapse for the patient & family	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What effect does a palliative prognosis have on the patient?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Support of carers	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Relatives role in nursing an oncology patient	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Spouse/significant others experiences and supportive role	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Effects of illness on family especially spouse/partner?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the psychological issues for sibling donors?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What is the donor experience?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Nurses' role in supporting the donor	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What are the short and long term side-effects of GCSF on donors?	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

Nurses' Role	**How important is this topic for haemato-oncology nursing research?**							**How important is this topic for haemato-oncology nurse education?**						
	Low						**High**	**Low**						**High**
Should follow up of haematology patients be nurse led?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How effective/successful are nurse led services?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Development of extended role for nurses in haemato-oncology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Nurses' role in care of haemato-oncology patient in BMT workup	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Nurses undertaking bone marrow aspiration - will it improve patient experience?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Do haematology patients with malignant disease get sufficient specialist nurse support?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
What access do patients in the UK have to a CNS?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
How effective is the CNS role in haemato-oncology?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Role of the nurse consultant in haemato-oncology	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Career development for haemato-oncology nurses	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Critical care skills are they an essential requirement for haematology/BMT nurses?	1	2	3	4	5	6	7	1	2	3	4	5	6	7
Minimum skills/requirements for UK haematology nurses/researchers/managers	1	2	3	4	5	6	7	1	2	3	4	5	6	7

Please indicate the research statement/question you perceive to be most important in this category by placing the number 1 next to the appropriate item

If you think there are important research priorities that have been omitted from this questionnaire please list these below.

Thank you for you time and cooperation in completing this questionnaire

Please return your completed questionnaire in the enclosed SAE by 25th September 2004

Delphi Study Pilot

1) How long did it take you to complete the questionnaire?

2) How easy was the questionnaire to complete? (Please circle the most appropriate answer)

Very easy   Easy   Difficult   Very Difficult

3) Were the instructions for completing the questionnaire clear?

4) If your answer to question 5 was no please state which instructions you found unclear.

7) Did you find the format of the questionnaire clear?

8) If your answer to question 7 was no please say why you found the format unclear.

Please feel free to highlight on the questionnaire any areas you feel are unclear.

Appendix 9:
Round 2: List of Ranked Priorities

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
1	56	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	81.2	6
2	50	Long-term health risks of nurses exposed to chemotherapy/antibiotics	80.3	6
3	9	What is nurses' knowledge of neutropenic sepsis?	77.8	6
4	18	Are staff shortages detrimental to practical/emotional support?	75.2	6
4	148	What do patients expect/require from nurses?	75.2	6
6	63	Making decision when active treatment ends and palliative treatment begins	74.4	7
7	2	Access to haematological nurse education/courses	73.5	6
10	62	When to actively treat and when to withdraw treatment	72.7	6
10	5	How can chemotherapy training and administration be standardised throughout the UK?	72.7	5
10	91	Management and care of neutropenic patients	72.7	6
10	157	Psychological effects of relapse for the patient & family	72.7	6
10	168	How effective/successful are nurse-led services?	72.7	6
13	117	Quality of life - What does it really mean to the patient?	71.8	6
13	177	Critical care skills are they an essential requirement for haematology/BMT nurses?	71.8	6
17	11	What is nurses' awareness of transfusion reactions?	70.9	6
17	122	How could nurses improve support for patients?	70.9	6
17	52	Effect of communication good/bad on patients	70.9	6
17	59	Provision of information for children of adults with a haematological cancer	70.9	6
17	178	Minimum skills/requirements for UK haematology nurses/researchers/managers	70.9	6
21	4	How can high standards/levels of knowledge in cytotoxic administration be maintained?	70.1	6
21	16	What is the effect of staffing levels and skill mix on outcomes of care?	70.1	6
21	90	How can prevention of infection measures be improved?	70.1	6
21	109	How can the side-effects of chemotherapy be reduced?	70.1	6
24	6	Are safety precautions in the administration of cytotoxic drugs safe enough?	69.2	6
24	151	Effect of low staff morale and staffing on experiences of isolated patient	69.2	6
28	55	Timeliness/quality/amount of information at diagnosis and relapse	68.4	6
28	78	Clear guidelines on mucositis management	68.4	5
28	81	What is best practice in protective isolation care? Is there a best practice?	68.4	6
28	121	What are the psychosocial support needs of patients with haematological cancers and their families?	68.4	5
28	169	Development of extended role for nurses in haemato-oncology	68.4	6
28	174	How effective is the CNS role in haemato-oncology?	68.4	6
33	38	Transition from curative to palliative care & treatment	67.6	6

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
33	61	Education and pre-assessment of patients having chemotherapy	67.6	6
33	75	National guidelines/standards of care for central venous catheters including dressings, cleaning	67.6	6
38	57	Information giving and patient empowerment	66.7	6
38	76	Develop evidence base for optimal care/ use/ problem solving of central venous catheters	66.7	6
38	79	Oral care protocol - what's best?	66.7	6
38	104	Disease and treatment related fatigue	66.7	6
38	118	Long-term survival anxiety when returning to clinic for follow up	66.7	5
38	158	What effect does a palliative prognosis have on the patient?	66.7	6
38	176	Career development for haemato-oncology nurses	66.7	6
43	146	Patient experiences of symptom control	65.8	6
43	66	Does the patient receive sufficient information to provide informed patient consent?	65.8	6
43	124	Psychological effects of haematological cancers	65.8	6
43	136	What is the psychological impact of BMT?	65.8	6
48	58	What information do patients require on specific aspects of care?	65	6
48	89	How can clinical research be implemented into practice?	65	6
48	94	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	65	6
48	149	How important to patients is access to a CNS?	65	5
48	93	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	65	6
52	28	What are the benefits and limitations of increased outpatient and home care?	64.1	6
52	108	Management of GVHD treatment complications	64.1	6
52	135	What is the value of counselling for BMT patients pre & post transplant?	64.1	6
52	154	Impact of haematological cancer on family dynamics/relationships	64.1	6
57	43	Psychological effects on health care professionals working in BMT/haematology	63.3	5
57	119	What are the effects of surviving long term?	63.3	6
57	7	Is depth of knowledge of nurses administering chemotherapy sufficient?	63.3	6
57	134	Should a psychologist/counsellor be involved at ward level for patients & relatives?	63.3	6
57	140	How can patient experience of diagnosis and follow up be improved?	63.3	6
57	162	Effects of illness on family especially spouse/partner?	63.3	6
64	8	What is nurses' awareness of drug related toxicity?	62.4	6
64	21	Are patient outcomes improved through multi-disciplinary team working?	62.4	5
64	37	Are palliative care needs being addressed?	62.4	6
64	45	What are the psychological support needs of nurses & other health care professionals?	62.4	6

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
64	73	Truth telling in BMT/PBSCT	62.4	6
64	156	Psychological effects of intensive treatment on patients & families	62.4	6
64	161	Spouse/significant others' experiences and supportive role	62.4	6
64	172	Do haematology patients with malignant disease get sufficient specialist nurse support?	62.4	6
72	53	Breaking bad news. Who does the patient prefer nurses or drs?	61.5	6
72	71	How can end of journey decision making with patients be improved?	61.5	6
72	82	Development of evidence base for optimal control of nausea & vomiting	61.5	6
72	27	Safety of care when haematology combined with another speciality	61.5	6
72	69	What is the nurses' advocacy role for haemato-oncology patients?	61.5	5
72	123	What are the psychological needs of the older haematology patient?	61.5	6
72	175	Role of the nurse consultant in haemato-oncology	61.5	6
76	92	Long-term follow up/rehabilitation for patients with haematological cancers	60.7	6
76	120	What are the short and long term psychological effects of isolation?	60.7	6
80	1	Educational needs of nurses at 3 levels novice, developing practice, expert	59.8	7
80	41	Palliative care - when should it be initiated?	59.8	5
80	64	Appropriate use of blood transfusion in haematological palliative care	59.8	6
80	138	What is the lived experience of receiving diagnosis/achieving remission?	59.8	6
80	144	Patients' views of where they are treated	59.8	6
80	166	What are the short and long term side-effects of GCSF on donors?	59.8	6
85	51	Is time available to identify patient concerns?	59	6
85	167	Should follow up of haematology patients be nurse led?	59	6
85	170	Nurses' role in care of haemato-oncology patient in BMT workup	59	6
88	87	Treatment safety including blood	58.1	6
88	97	How can needs of older inpatients with myeloma & CLL be best met?	58.1	6
88	98	Are fertility issues addressed?	58.1	6
88	141	Patient experience of current care	58.1	5
93	29	Improving services at home eg patient involvement and treatment options	57.3	6
93	31	How can continuity of care be improved?	57.3	6
93	54	Nurses' reactions to dealing with emotional questions	57.3	6
93	68	How do patients make decisions about clinical trials at diagnosis?	57.3	6
93	77	Implementing an effective audit tool to monitor Hickman line care	57.3	6
93	105	Control of gastric symptoms during allogeneic BMT	57.3	6

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
100	137	What effect do haematological cancers have on mood/personality?	56.4	6
100	155	Family support for patients having BMT/lengthy chemotherapy	56.4	6
100	22	What impact do different chemotherapy regimes have on nurse workload?	56.4	5
100	40	Consistency of practice between palliative care and haematology	56.4	6
100	95	Venous access assessment in ensuring correct device used	56.4	6
100	127	What short and long term psychosocial coping strategies do patients use?	56.4	6
100	129	What is the correlation between myelosuppression and depression for the isolated patient?	56.4	5
100	147	Patient experiences of hospitalisation	56.4	6
107	112	Is pain control during bone marrow biopsies effective?	55.6	6
107	139	Patient view of the meaning of a cancer diagnosis	55.6	6
107	150	How do patients perceive the role of nurse specialist?	55.6	6
107	171	Nurses undertaking bone marrow aspiration - will it improve patient experience?	55.6	6
107	113	Are sexuality issues addressed?	55.6	6
112	25	Is there a difference in care given in cancer centres and District General Hospitals?	54.7	6
112	65	Ethical issues of treatment of the elderly	54.7	5
112	80	What are the most effective mouthwashes during chemotherapy?	54.7	5
112	86	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	54.7	5
112	163	What are the psychological issues for sibling donors?	54.7	6
117	19	Recruitment and retention of all grades haematology/BMT nurses	53.9	6
117	24	Blood product replacement - are we over transfusing?	53.9	5
117	39	How can better links with palliative care services be facilitated?	53.9	6
117	114	What is the extent/impact of sexual dysfunction?	53.9	5
117	142	Lack of psychosocial care for patients and families	53.9	6
123	100	Immediate care post BMT	53	6
123	102	Dealing with relatively young patients	53	5
123	106	Skin care post allogeneic BMT	53	6
123	125	Should specific criteria be used for pre-transplant psychological assessment?	53	6
123	145	Experiences of patients with failed stem cell harvest	53	6
123	173	What access do patients in the UK have to a CNS?	53	6
128	160	Relatives' role in nursing an oncology patient	52.1	6
128	60	Patients' and carers' education on physical aspects of care	52.1	6
128	153	Impact of myeloproliferative disorders on lives	52.1	6

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
128	107	Management of veno-occlusive crisis	52.1	5
131	96	Central venous catheters - do risks outweigh the benefits?	50.4	6
134	14	Training of specialist nurses	50.4	5
134	17	Does senior staff ratio ie sisters and above improve patient care?	50.4	5
134	46	Staff support and counselling	50.4	6
134	48	Is effective clinical supervision available to nurses in haemato-oncology?	50.4	5
134	130	How do patients cope with fatigue?	50.4	6
134	159	Support of carers	50.4	6
140	88	Safety issues related to nebulised pentamidine administration	49.6	5
140	67	How can informed consent be ensured if the patient is incapacitated?	49.6	6
140	83	What is best practice for nursing management of day care patients?	49.6	6
142	10	What is nurses' awareness of viral complications post BMT/PBSCT?	48.7	6
142	70	How can patients have more autonomy?	48.7	5
142	85	What nursing theory should underpin haematology nursing practice?	48.7	6
142	99	Pre-BMT care	48.7	5
145	36	Impact of the inevitable reduction of blood donors for haematology patients	47.9	5
145	110	Elimination problems due to treatment	47.9	5
148	44	Does BMT burnout in nurses exist today?	47	6
148	126	Measure psychological interventions for haematology patients	47	5
148	164	What is the donor experience?	47	6
148	165	Nurses' role in supporting the donor	47	5
151	115	Spirituality	46.2	5
151	152	What do patients perceive as the benefits of having a bone marrow transplant?	46.2	5
153	133	Ongoing psychological care from hospital to home	45.3	5
153	143	Haematology patients' views on admission to an intensive care unit	45.3	6
156	3	Educating general nurses of importance of haematology	44.4	4
156	13	What is the impact of specialist education?	44.4	5
156	32	Does collaboration exist in haematology between drs and nurses?	44.4	5
156	103	What is the role of alternative therapies?	44.4	6
159	49	How staff feel about the workplace	43.6	5
159	131	What difficulties do patients have with compliance in taking long-term medication?	43.6	6
161	26	Lack of specialist care in rural communities	42.7	5

Rank	Question	Ranked Priorities 6 & 7 scores	%	Median
162	30	Issues in shared care - is it effective?	41.9	5
162	116	Cultural Issues	41.9	6
164	84	Prevention of reactions to blood/platelet transfusions	41	5
164	47	Availability of training and support and effects on stress development	41	7
164	74	Department of Health Improving Outcomes Guidelines are they making a difference?	41	6
166	101	Exercise and fitness during and after transplant	39.3	5
166	128	Mental illness in BMT	39.3	6
168	23	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	38.5	6
169	15	Support/training of research nurses	37.6	6
170	33	Should haematology be separate from oncology?	36.8	6
171	42	Gaining enthusiasm from health professionals for clinical trials/research	35.9	6
171	72	Ethical issues related to DNA technologies	35.9	6
173	34	When is appropriate time to refer to Macmillan services?	35	6
174	111	Alopecia	34.2	6
175	20	How can staff be effectively rotated through a cancer network?	32.5	6
176	35	Do we overuse blood tests? Especially in lymphoma	29.1	5
177	12	Training on non-clinical issues eg benefits?	19.7	5
178	132	Role of hypnotherapy & psychoneuroimmunology	18.8	6

Appendix 10:
Round 3: First Priority Scores by Category and Second Round Rank

Rank (2nd round)	Ist priorities Education	%
3	What is nurses' knowledge of neutropenic sepsis?	28.2
10	How can chemotherapy training and administration be standardised throughout the UK?	20.4
57	Is depth of knowledge of nurses administering chemotherapy sufficient?	9.7
21	How can high standards/levels of knowledge in cytotoxic administration be maintained?	6.8
156	Educating general nurses of importance of haematology	6.8
7	Access to haematological nurse education/courses	4.9
64	What is nurses' awareness of drug related toxicity?	3.9
80	Educational needs of nurses at 3 levels novice, developing practice, expert	3.9
134	Training of specialist nurses	3.9
17	What is nurses' awareness of transfusion reactions?	2.9
156	What is the impact of specialist education?	2.9
24	Are safety precautions in the administration of cytotoxic drugs safe enough?	2.9
169	Support/training of research nurses	1
142	What is nurses' awareness of viral complications post BMT/PBSCT?	0
177	Training on non-clinical issues eg benefits?	0

Rank (2nd round)	**Service Delivery and Organisation of Care**	**%**
21	What is the effect of staffing levels and skill mix on outcomes of care?	16.5
4	Are staff shortages detrimental to practical/emotional support?	16.5
33	Transition from curative to palliative care & treatment	14.6
72	Safety of care when haematology combined with another speciality	6.8
112	Is there a difference in care given in cancer centres and District General Hospitals?	6.8
52	What are the benefits and limitations of increased outpatient and home care?	5.8
117	Blood product replacement - are we over transfusing?	5.8
117	Recruitment and retention of all grades haematology/BMT nurses	4.9
80	Palliative care - when should it be initiated?	3.9
64	Are patient outcomes improved through multi-disciplinary team working?	2.9
64	Are palliative care needs being addressed?	2.9
100	What impact do different chemotherapy regimes have on nurse workload?	2.9
170	Should haematology be separate from oncology?	2.9
93	How can continuity of care be improved?	1.9
117	How can better links with palliative care services be facilitated?	1
134	Does senior staff ratio ie sisters and above improve patient care?	1
145	Impact of the inevitable reduction of blood donors for haematology patients	1
162	Issues in shared care - is it effective?	1
171	Gaining enthusiasm from health professionals for clinical trials/research	1
93	Improving services at home eg patient involvement and treatment options	0
100	Consistency of practice between palliative care and haematology	0
156	Does collaboration exist in haematology between drs and nurses?	0
161	Lack of specialist care in rural communities	0
168	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	0
173	When is appropriate time to refer to Macmillan services?	0
175	How can staff be effectively rotated through a cancer network?	0
176	Do we overuse blood tests? Especially in lymphoma	0

Rank (2nd round)	Effects of Role on Nurses' Health and Support Needs	%
2	Long-term health risks of nurses exposed to chemotherapy/antibiotics	44.7
64	What are the psychological support needs of nurses & other health care professionals?	14.6
134	Is effective clinical supervision available to nurses in haemato-oncology?	13.6
57	Psychological effects on health care professionals working in BMT/haematology	11.7
164	Availability of training and support and effects on stress development	5.8
148	Does BMT burnout in nurses exist today?	3.9
134	Staff support and counselling	2.9
159	How staff feel about the workplace	2.9

Rank (2nd round)	Communication/Patient Information and Education	%
1	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	46.6
17	Effect of communication good/bad on patients	11.7
72	Breaking bad news. Who does the patient prefer nurses or drs?	7.8
28	Timeliness/quality/amount of information at diagnosis and relapse	6.8
38	Information giving and patient empowerment	5.8
17	Provision of information for children of adults with a haematological cancer	4.9
48	What information do patients require on specific aspects of care?	4.9
33	Education and pre-assessment of patients having chemotherapy	3.9
85	Is time available to identify patient concerns?	3.9
93	Nurses' reactions to dealing with emotional questions	1.9
128	Patients' and carers' education on physical aspects of care	1

Rank (2nd round)	Ethical Decision Making	%
6	Making decision when active treatment ends and palliative treatment begins	32
10	When to actively treat and when to withdraw treatment	21.4
43	Does the patient receive sufficient information to provide informed patient consent?	18.4
64	Truth telling in BMT/PBSCT	4.9
72	What is the nurses' advocacy role for haemato-oncology patients?	4.9
80	Appropriate use of blood transfusion in haematological palliative care	4.9
72	How can end of journey decision making with patients be improved?	4.9
93	How do patients make decisions about clinical trials at diagnosis?	3.9
112	Ethical issues of treatment of the elderly	1.9
142	How can patients have more autonomy?	1
171	Ethical issues related to DNA technologies	1
140	How can informed consent be ensured if the patient is incapacitated?	0

Rank (2nd round)	**Utilising Knowledge and Developing the Evidence Base for Practice**	**%**
28	What is best practice in protective isolation care? Is there a best practice?	27.2
33	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	21.4
28	Clear guidelines on mucositis management	11.7
38	Develop evidence base for optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	8.7
164	Department of Health Improving Outcomes Guidelines are they making a difference?	6.8
93	Implementing an effective audit tool to monitor Hickman line care	4.9
142	What nursing theory should underpin haematology nursing practice?	3.9
72	Development of evidence base for optimal control of nausea & vomiting	2.9
38	Oral care protocol - what's best?	2.9
140	What is best practice for nursing management of day care patients?	2.9
48	How can clinical research be implemented into practice?	1.9
88	Treatment safety including blood	1.9
112	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	1
112	What are the most effective mouthwashes during chemotherapy?	0
140	Safety issues related to nebulised pentamidine administration	0
164	Prevention of reactions to blood/platelet transfusions	0

Rank (2nd round)	Nursing Interventions and Care	%
10	Management and care of neutropenic patients	46.6
48	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	9.7
21	How can prevention of infection measures be improved?	9.7
76	Long-term follow up/rehabilitation for patients with haematological cancers	8.7
100	Venous access assessment in ensuring correct device used	7.8
48	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	3.9
88	Are fertility issues addressed?	2.9
123	Dealing with relatively young patients	1.9
131	Central venous catheters - do risks outweigh the benefits?	1.9
142	Pre-BMT care	1.9
88	How can needs of older inpatients with myeloma & CLL be best met?	1
156	What is the role of alternative therapies?	1
166	Exercise and fitness during and after transplant	1
123	Immediate care post BMT	0

Rank (2nd round)	Symptom Management	%
21	How can the side-effects of chemotherapy be reduced?	50.5
38	Disease and treatment related fatigue	18.4
52	Management of GVHD treatment complications	8.7
93	Control of gastric symptoms during allogeneic BMT	6.8
145	Elimination problems due to treatment	5.8
107	Is pain control during bone marrow biopsies effective?	4.9
174	Alopecia	1.9
123	Skin care post allogeneic BMT	1.9
128	Management of veno-occlusive crisis	1

Rank (2nd round)	Psychosocial Wellbeing and Support	%
13	Quality of life - What does it really mean to the patient?	32
28	What are the psychosocial support needs of patients with haematological cancers and their families?	12.6
17	How could nurses improve support for patients?	8.7
38	Long-term survival anxiety when returning to clinic for follow up	5.8
43	Psychological effects of haematological cancers	5.8
52	What is the value of counselling for BMT patients pre & post transplant?	3.9
57	What are the effects of surviving long term?	3.9
100	What short and long term psychosocial coping strategies do patients use?	3.9
57	Should a psychologist/counsellor be involved at ward level for patients & relatives?	3.9
100	What effect do haematological cancers have on mood/personality?	2.9
100	What is the correlation between myelosuppression and depression for the isolated patient?	1.9
123	Should specific criteria be used for pre-transplant psychological assessment?	1.9
134	How do patients cope with fatigue?	1.9
148	Measure psychological interventions for haematology patients	1.9
162	Cultural issues	1.9
43	What is the psychological impact of BMT?	1
76	What are the short and long term psychological effects of isolation?	1
107	Are sexuality issues addressed?	1
151	Spirituality	1
153	Ongoing psychological care from hospital to home	1
159	What difficulties do patients have with compliance in taking long term medication?	1
166	Mental illness in BMT	1
72	What are the psychological needs of the older haematology patient?	0
117	What is the extent/impact of sexual dysfunction?	0
178	Role of hypnotherapy & psychoneuroimmunology	0

Rank (2nd round)	Patient and Family Experience	%
4	What do patients expect/require from nurses?	28.2
48	How important to patients is access to a CNS?	8.7
24	Effect of low staff morale and staffing on experiences of isolated patient	7.8
64	Psychological effects of intensive treatment on patients & families	7.8
10	Psychological effects of relapse for the patient & family	6.8
80	What are the short and long term side-effects of GCSF on donors?	6.8
57	How can patient experience of diagnosis and follow up be improved?	4.9
57	Effects of illness on family especially spouse/partner?	2.9
107	How do patients perceive the role of nurse specialist?	2.9
38	What effect does a palliative prognosis have on the patient?	2.9
52	Impact of haematological cancer on family dynamics/relationships	2.9
128	Impact of myeloproliferative disorders on lives	2.9
153	Haematology patients' views on admission to an intensive care unit	2.9
100	Family support for patients having BMT/lengthy chemotherapy	1.9
100	Patient experiences of hospitalisation	1.9
117	Lack of psychosocial care for patients and families	1.9
112	What are the psychological issues for sibling donors?	1
88	Patient experience of current care	1
80	Patients' views of where they are treated	1
107	Patient view of the meaning of a cancer diagnosis	1
148	What is the donor experience?	1
43	Patient experiences of symptom control	1
64	Spouse/significant others' experiences and supportive role	0
80	What is the lived experience of receiving diagnosis/achieving remission?	0
123	Experiences of patients with failed stem cell harvest	0
128	Relatives' role in nursing an oncology patient	0
134	Support of carers	0
148	Nurses' role in supporting the donor	0
151	What do patients perceive as the benefits of having a bone marrow transplant?	0

Rank (2nd round)	Nurses' Role	%
10	How effective/successful are nurse-led services?	29.1
13	Critical care skills are they an essential requirement for haematology/BMT nurses?	18.4
64	Do haematology patients with malignant disease get sufficient specialist nurse support?	12.6
28	How effective is the CNS role in haemato-oncology?	7.8
85	Should follow up of haematology patients be nurse led?	7.8
17	Minimum skills/requirements for UK haematology nurses/researchers/managers	6.8
38	Career development for haemato-oncology nurses	4.9
107	Nurses undertaking bone marrow aspiration - will it improve patient experience?	3.9
28	Development of extended role for nurses in haemato-oncology	2.9
72	Role of the nurse consultant in haemato-oncology	1.9
123	What access do patients in the UK have to a CNS?	1.9
85	Nurses' role in care of haemato-oncology patient in BMT workup	1

Appendix 11:
Round 3: Second Priority Scores by Category and Second Round Rank

Rank **(2nd round)**	**2nd Priorities** **Education**	**%**
10	How can chemotherapy training and administration be standardised throughout the UK?	17.5
21	How can high standards/levels of knowledge in cytotoxic administration be maintained?	15.5
57	Is depth of knowledge of nurses administering chemotherapy sufficient?	13.6
3	What is nurses' knowledge of neutropenic sepsis?	11.7
17	What is nurses' awareness of transfusion reactions?	9.7
7	Access to haematological nurse education/courses	8.7
24	Are safety precautions in the administration of cytotoxic drugs safe enough?	6.8
156	Educating general nurses of importance of haematology	4.9
80	Educational needs of nurses at 3 levels novice, developing practice, expert	4.9
156	What is the impact of specialist education?	2.9
64	What is nurses' awareness of drug related toxicity?	1
142	What is nurses' awareness of viral complications post BMT/PBSCT?	1
134	Training of specialist nurses	0
169	Support/training of research nurses	0
177	Training on non-clinical issues eg benefits?	0

Rank (2nd round)	Service Delivery and Organisation of Care	%
21	What is the effect of staffing levels and skill mix on outcomes of care?	21.4
4	Are staff shortages detrimental to practical/emotional support?	9.7
100	What impact do different chemotherapy regimes have on nurse workload?	9.7
112	Is there a difference in care given in cancer centres and District General Hospitals?	7.8
52	What are the benefits and limitations of increased outpatient and home care?	6.8
33	Transition from curative to palliative care & treatment	4.9
72	Safety of care when haematology combined with another speciality	4.9
93	How can continuity of care be improved?	4.9
117	Blood product replacement - are we over transfusing?	3.9
162	Issues in shared care - is it effective?	3.9
64	Are palliative care needs being addressed?	2.9
134	Does senior staff ratio ie sisters and above improve patient care?	2.9
93	Improving services at home eg patient involvement and treatment options	2.9
64	Are patient outcomes improved through multi-disciplinary team working?	1.9
117	How can better links with palliative care services be facilitated?	1.9
156	Does collaboration exist in haematology between drs and nurses?	1.9
161	Lack of specialist care in rural communities	1.9
100	Consistency of practice between palliative care and haematology	1.9
175	How can staff be effectively rotated through a cancer network?	1
80	Palliative care - when should it be initiated?	1
176	Do we overuse blood tests? Especially in lymphoma	1
117	Recruitment and retention of all grades haematology/BMT nurses	1
170	Should haematology be separate from oncology?	0
145	Impact of the inevitable reduction of blood donors for haematology patients	0
171	Gaining enthusiasm from health professionals for clinical trials/research	0
168	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	0
173	When is appropriate time to refer to Macmillan services?	0

Rank (2nd round)	Effects of Role on Nurses' Health and Support Needs	%
57	Psychological effects on health care professionals working in BMT/haematology	21.4
64	What are the psychological support needs of nurses & other health care professionals?	20.4
134	Is effective clinical supervision available to nurses in haemato-oncology?	17.5
2	Long-term health risks of nurses exposed to chemotherapy/antibiotics	13.6
134	Staff support and counselling	8.7
159	How staff feel about the workplace	8.7
164	Availability of training and support and effects on stress development	4.9
148	Does BMT burnout in nurses exist today?	4.9

Rank (2nd round)	Communication/Patient Information and Education	%
17	Effect of communication good/bad on patients	18.4
1	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	17.5
33	Education and pre-assessment of patients having chemotherapy	13.6
85	Is time available to identify patient concerns?	8.7
72	Breaking bad news. Who does the patient prefer nurses or drs?	8.7
28	Timeliness/quality/amount of information at diagnosis and relapse	7.8
17	Provision of information for children of adults with a haematological cancer	5.8
38	Information giving and patient empowerment	5.8
93	Nurses' reactions to dealing with emotional questions	5.8
48	What information do patients require on specific aspects of care?	5.8
128	Patients' and carers' education on physical aspects of care	1

Rank (2nd round)	Ethical Decision Making	%
10	When to actively treat and when to withdraw treatment	19.4
6	Making decision when active treatment ends and palliative treatment begins	17.5
72	How can end of journey decision making with patients be improved?	15.5
43	Does the patient receive sufficient information to provide informed patient consent?	13.6
72	What is the nurses' advocacy role for haemato-oncology patients?	7.8
64	Truth telling in BMT/PBSCT	6.8
80	Appropriate use of blood transfusion in haematological palliative care	6.8
93	How do patients make decisions about clinical trials at diagnosis?	4.9
142	How can patients have more autonomy?	1.9
171	Ethical issues related to DNA technologies	1.9
140	How can informed consent be ensured if the patient is incapacitated?	1.9
112	Ethical issues of treatment of the elderly	1

Rank (2nd round)	Utilising Knowledge and Developing the Evidence Base for Practice	%
33	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	14.6
28	What is best practice in protective isolation care? Is there a best practice?	14.6
38	Develop evidence base for optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	9.7
28	Clear guidelines on mucositis management	9.7
72	Development of evidence base for optimal control of nausea & vomiting	7.8
48	How can clinical research be implemented into practice?	7.8
38	Oral care protocol - what's best?	6.8
140	What is best practice for nursing management of day care patients?	6.8
112	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	4.9
93	Implementing an effective audit tool to monitor Hickman line care	3.9
112	What are the most effective mouthwashes during chemotherapy?	2.9
164	Department of Health Improving Outcomes Guidelines are they making a difference?	1.9
88	Treatment safety including blood	1.9
140	Safety issues related to nebulised pentamidine administration	1.9
142	What nursing theory should underpin haematology nursing practice?	1.9
164	Prevention of reactions to blood/platelet transfusions	1.9

Rank (2nd round)	Nursing Interventions and Care	%
21	How can prevention of infection measures be improved?	16.5
48	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	12.6
48	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	12.6
10	Management and care of neutropenic patients	11.7
76	Long-term follow up/rehabilitation for patients with haematological cancers	10.7
88	Are fertility issues addressed?	9.7
88	How can needs of older inpatients with myeloma & CLL be best met?	5.8
166	Exercise and fitness during and after transplant	3.9
123	Immediate care post-BMT	3.9
100	Venous access assessment in ensuring correct device used	2.9
131	Central venous catheters - do risks outweigh the benefits?	2.9
123	Dealing with relatively young patients	1.9
156	What is the role of alternative therapies?	1.9
142	Pre-BMT care	1

Rank (2nd round)	Symptom Management	%
38	Disease and treatment related fatigue	26.2
21	How can the side-effects of chemotherapy be reduced?	18.4
52	Management of GVHD treatment complications	16.5
107	Is pain control during bone marrow biopsies effective?	12.6
145	Elimination problems due to treatment	9.7
128	Management of veno-occlusive crisis	6.8
93	Control of gastric symptoms during allogeneic BMT	5.8
174	Alopecia	1.9
123	Skin care post allogeneic BMT	1.9

Rank (2nd round)	Psychosocial Wellbeing and Support	%
28	What are the psychosocial support needs of patients with haematological cancers and their families?	12.6
57	Should a psychologist/counsellor be involved at ward level for patients & relatives?	11.7
107	Are sexuality issues addressed?	8.7
57	What are the effects of surviving long term?	7.8
13	Quality of life - What does it really mean to the patient?	6.8
43	Psychological effects of haematological cancers	5.8
134	How do patients cope with fatigue?	5.8
38	Long-term survival anxiety when returning to clinic for follow up	5.8
43	What is the psychological impact of BMT?	4.9
17	How could nurses improve support for patients?	4.9
76	What are the short and long term psychological effects of isolation?	3.9
153	Ongoing psychological care from hospital to home	3.9
117	What is the extent/impact of sexual dysfunction?	2.9
162	Cultural issues	2.9
52	What is the value of counselling for BMT patients pre & post transplant?	2.9
166	Mental illness in BMT	2.9
100	What is the correlation between myelosuppression and depression for the isolated patient?	1
100	What effect do haematological cancers have on mood/personality?	1
100	What short and long term psychosocial coping strategies do patients use?	1
148	Measure psychological interventions for haematology patients	1
151	Spirituality	1
178	Role of hypnotherapy & psychoneuroimmunology	1
72	What are the psychological needs of the older haematology patient?	0
123	Should specific criteria be used for pre-transplant psychological assessment?	0
159	What difficulties do patients have with compliance in taking long-term medication?	0

Rank (2nd round)	Patient and Family Experience	%
4	What do patients expect/require from nurses?	12.6
10	Psychological effects of relapse for the patient & family	8.7
24	Effect of low staff morale and staffing on experiences of isolated patient	7.8
43	Patient experiences of symptom control	6.8
80	What are the short and long term side-effects of GCSF on donors?	6.8
112	What are the psychological issues for sibling donors?	6.8
57	Effects of illness on family especially spouse/partner?	5.8
88	Patient experience of current care	5.8
80	Patients' views of where they are treated	4.9
107	How do patients perceive the role of nurse specialist?	4.9
48	How important to patients is access to a CNS?	4.9
38	What effect does a palliative prognosis have on the patient?	4.9
57	How can patient experience of diagnosis and follow up be improved?	2.9
52	Impact of haematological cancer on family dynamics/relationships	1.9
64	Psychological effects of intensive treatment on patients & families	1.9
100	Family support for patients having BMT/lengthy chemotherapy	1.9
100	Patient experiences of hospitalisation	1.9
123	Experiences of patients with failed stem cell harvest	1.9
64	Spouse/significant others' experiences and supportive role	1
80	What is the lived experience of receiving diagnosis/achieving remission?	1
107	Patient view of the meaning of a cancer diagnosis	1
128	Relatives' role in nursing an oncology patient	1
128	Impact of myeloproliferative disorders on lives	1
134	Support of carers	1
148	What is the donor experience?	1
117	Lack of psychosocial care for patients and families	0
148	Nurses' role in supporting the donor	0
151	What do patients perceive as the benefits of having a bone marrow transplant?	0
153	Haematology patients' views on admission to an intensive care unit	0

Rank (2nd round)	Nurses' Role	%
28	How effective is the CNS role in haemato-oncology?	15.5
13	Critical care skills are they an essential requirement for haematology/BMT nurses?	13.6
17	Minimum skills/requirements for UK haematology nurses/researchers/managers	13.6
28	Development of extended role for nurses in haemato-oncology	12.6
10	How effective/successful are nurse-led services?	12.6
64	Do haematology patients with malignant disease get sufficient specialist nurse support?	7.8
85	Should follow up of haematology patients be nurse led?	6.8
38	Career development for haemato-oncology nurses	5.8
107	Nurses undertaking bone marrow aspiration - will it improve patient experience?	5.8
72	Role of the nurse consultant in haemato-oncology	1.9
123	What access do patients in the UK have to a CNS?	1.9
85	Nurses' role in care of haemato-oncology patient in BMT workup	1

Appendix 12:
Round 3: Third Priority Scores by Category and Second Round Rank

Rank (2nd round)	3rd Priorities Education	%
3	What is nurses' knowledge of neutropenic sepsis?	14.6
10	How can chemotherapy training and administration be standardised throughout the UK?	9.7
57	Is depth of knowledge of nurses administering chemotherapy sufficient?	8.7
21	How can high standards/levels of knowledge in cytotoxic administration be maintained?	8.7
80	Educational needs of nurses at 3 levels novice, developing practice, expert	8.7
7	Access to haematological nurse education/courses	7.8
156	Educating general nurses of importance of haematology	7.8
24	Are safety precautions in the administration of cytotoxic drugs safe enough?	6.8
134	Training of specialist nurses	5.8
142	What is nurses' awareness of viral complications post-BMT/PBSCT?	5.8
156	What is the impact of specialist education?	4.9
17	What is nurses' awareness of transfusion reactions?	3.9
64	What is nurses' awareness of drug related toxicity?	1.9
177	Training on non-clinical issues eg benefits?	1.9
169	Support/training of research nurses	1

Rank (2nd round)	Service Delivery and Organisation of Care	%
4	Are staff shortages detrimental to practical/emotional support?	9.7
21	What is the effect of staffing levels and skill mix on outcomes of care?	8.7
100	What impact do different chemotherapy regimes have on nurse workload?	6.8
112	Is there a difference in care given in cancer centres and District General Hospitals?	5.8
33	Transition from curative to palliative care & treatment	6.8
72	Safety of care when haematology combined with another speciality	5.8
175	How can staff be effectively rotated through a cancer network?	5.8
52	What are the benefits and limitations of increased outpatient and home care?	4.9
117	Blood product replacement - are we over transfusing?	4.9
93	Improving services at home eg patient involvement and treatment options	3.9
145	Impact of the inevitable reduction of blood donors for haematology patients	3.9
64	Are patient outcomes improved through multi-disciplinary team working?	3.9
93	How can continuity of care be improved?	2.9
162	Issues in shared care - is it effective?	2.9
134	Does senior staff ratio ie sisters and above improve patient care?	2.9
156	Does collaboration exist in haematology between drs and nurses?	2.9
100	Consistency of practice between palliative care and haematology	2.9
117	Recruitment and retention of all grades haematology/BMT nurses	2.9
170	Should haematology be separate from oncology?	2.9
64	Are palliative care needs being addressed?	1.9
161	Lack of specialist care in rural communities	1.9
80	Palliative care - when should it be initiated?	1.9
176	Do we overuse blood tests? Especially in lymphoma	1.9
117	How can better links with palliative care services be facilitated?	1
171	Gaining enthusiasm from health professionals for clinical trials/research	0
168	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	0
173	When is appropriate time to refer to Macmillan services?	0

Rank (2nd round)	Effects of Role on Nurses' Health and Support Needs	%
164	Availability of training and support and effects on stress development	25.2
64	What are the psychological support needs of nurses & other health care professionals?	17.5
57	Psychological effects on health care professionals working in BMT/haematology	11.7
134	Is effective clinical supervision available to nurses in haemato-oncology?	10.7
159	How staff feel about the workplace	10.7
134	Staff support and counselling	9.7
2	Long-term health risks of nurses exposed to chemotherapy/antibiotics	8.7
148	Does BMT burnout in nurses exist today?	5.8

Rank (2nd round)	Communication/Patient Information and Education	%
28	Timeliness/quality/amount of information at diagnosis and relapse	14.6
17	Effect of communication good/bad on patients	13.6
33	Education and pre-assessment of patients having chemotherapy	10.7
48	What information do patients require on specific aspects of care?	10.7
85	Is time available to identify patient concerns?	9.7
72	Breaking bad news. Who does the patient prefer nurses or drs?	8.7
38	Information giving and patient empowerment	8.7
1	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	7.8
93	Nurses' reactions to dealing with emotional questions	6.8
17	Provision of information for children of adults with a haematological cancer	4.9
128	Patients' and carers' education on physical aspects of care	2.9

Rank (2nd round)	Ethical Decision Making	%
72	How can end of journey decision making with patients be improved?	17.5
43	Does the patient receive sufficient information to provide informed patient consent?	14.6
72	What is the nurses' advocacy role for haemato-oncology patients?	12.6
80	Appropriate use of blood transfusion in haematological palliative care	11.7
6	Making decision when active treatment ends and palliative treatment begins	10.7
112	Ethical issues of treatment of the elderly	9.7
10	When to actively treat and when to withdraw treatment	8.7
64	Truth telling in BMT/PBSCT	5.8
142	How can patients have more autonomy?	3.9
93	How do patients make decisions about clinical trials at diagnosis?	3.9
171	Ethical issues related to DNA technologies	1
140	How can informed consent be ensured if the patient is incapacitated?	0

Rank (2nd round)	Utilising Knowledge and Developing the Evidence Base for Practice	%
38	Oral care protocol - what's best?	11.7
33	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	11.7
28	What is best practice in protective isolation care? Is there a best practice?	8.7
28	Clear guidelines on mucositis management	8.7
88	Treatment safety including blood	7.8
38	Develop evidence base for optimal car/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	6.8
72	Development of evidence base for optimal control of nausea & vomiting	6.8
164	Department of Health Improving Outcomes Guidelines are they making a difference?	5.8
48	How can clinical research be implemented into practice?	4.9
140	What is best practice for nursing management of day care patients?	4.9
112	What are the most effective mouthwashes during chemotherapy?	3.9
140	Safety issues related to nebulised pentamidine administration	3.9
164	Prevention of reactions to blood/platelet transfusions	3.9
112	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	2.9
93	Implementing an effective audit tool to monitor Hickman line care	2.9
142	What nursing theory should underpin haematology nursing practice?	2.9

Rank (2nd round)	Nursing Interventions and Care	%
48	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	14.6
156	What is the role of alternative therapies?	10.7
48	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	9.7
21	How can prevention of infection measures be improved?	8.7
131	Central venous catheters - do risks outweigh the benefits?	8.7
76	Long-term follow up/rehabilitation for patients with haematological cancers	8.7
123	Dealing with relatively young patients	8.7
10	Management and care of neutropenic patients	5.8
88	Are fertility issues addressed?	5.8
88	How can needs of older inpatients with myeloma & CLL be best met?	5.8
166	Exercise and fitness during and after transplant	2.9
100	Venous access assessment in ensuring correct device used	2.9
142	Pre-BMT care	2.9
123	Immediate care post-BMT	1.9

Rank (2nd round)	Symptom Management	%
38	Disease and treatment related fatigue	21.4
107	Is pain control during bone marrow biopsies effective?	17.5
52	Management of GVHD treatment complications	16.5
174	Alopecia	11.7
145	Elimination problems due to treatment	9.7
93	Control of gastric symptoms during allogeneic BMT	9.7
21	How can the side-effects of chemotherapy be reduced?	8.7
128	Management of veno-occlusive crisis	1.9
123	Skin care post allogeneic BMT	1.9

Rank (2nd round)	**Psychosocial Wellbeing and Support**	%
17	How could nurses improve support for patients?	10.7
28	What are the psychosocial support needs of patients with haematological cancers and their families?	9.7
57	Should a psychologist/counsellor be involved at ward level for patients & relatives?	8.7
43	Psychological effects of haematological cancers	8.7
38	Long-term survival anxiety when returning to clinic for follow up	7.8
107	Are sexuality issues addressed?	6.8
134	How do patients cope with fatigue?	6.8
57	What are the effects of surviving long term?	4.9
13	Quality of life - What does it really mean to the patient?	4.9
76	What are the short and long term psychological effects of isolation?	4.9
52	What is the value of counselling for BMT patients pre & post transplant?	3.9
100	What effect do haematological cancers have on mood/personality?	3.9
153	Ongoing psychological care from hospital to home	2.9
117	What is the extent/impact of sexual dysfunction?	2.9
151	Spirituality	2.9
100	What is the correlation between myelosuppression and depression for the isolated patient?	2.9
162	Cultural issues	1.9
100	What short and long term psychosocial coping strategies do patients use?	1.9
43	What is the psychological impact of BMT?	1
166	Mental illness in BMT	1
148	Measure psychological interventions for haematology patients	1
178	Role of hypnotherapy & psychoneuroimmunology	0
72	What are the psychological needs of the older haematology patient?	0
123	Should specific criteria be used for pre-transplant psychological assessment?	0
159	What difficulties do patients have with compliance in taking long-term medication?	0

Rank (2nd round)	Patient and Family Experience	%
48	How important to patients is access to a CNS?	11.7
43	Patient experiences of symptom control	6.8
38	What effect does a palliative prognosis have on the patient?	6.8
134	Support of carers	6.8
10	Psychological effects of relapse for the patient & family	4.9
52	Impact of haematological cancer on family dynamics/relationships	4.9
64	Psychological effects of intensive treatment on patients & families	4.9
107	Patient view of the meaning of a cancer diagnosis	4.9
24	Effect of low staff morale and staffing on experiences of isolated patient	4.9
80	What are the short and long term side-effects of GCSF on donors?	3.9
107	How do patients perceive the role of nurse specialist?	3.9
80	What is the lived experience of receiving diagnosis/achieving remission?	3.9
4	What do patients expect/require from nurses?	3.9
112	What are the psychological issues for sibling donors?	2.9
80	Patients' views of where they are treated	2.9
57	How can patient experience of diagnosis and follow up be improved?	2.9
100	Patient experiences of hospitalisation	2.9
148	What is the donor experience?	2.9
57	Effects of illness on family especially spouse/partner?	2.9
100	Family support for patients having BMT/lengthy chemotherapy	1.9
128	Impact of myeloproliferative disorders on lives	1.9
151	What do patients perceive as the benefits of having a bone marrow transplant?	1.9
88	Patient experience of current care	1
123	Experiences of patients with failed stem cell harvest	1
64	Spouse/significant others' experiences and supportive role	1
128	Relatives' role in nursing an oncology patient	1
148	Nurses' role in supporting the donor	1
117	Lack of psychosocial care for patients and families	0
153	Haematology patients' views on admission to an intensive care unit	0

Rank **(2nd round)**	**Nurses' Role**	**%**
38	Career development for haemato-oncology nurses	14.6
10	How effective/successful are nurse-led services?	12.6
17	Minimum skills/requirements for UK haematology nurses/researchers/managers	12.6
28	Development of extended role for nurses in haemato-oncology	12.6
85	Should follow up of haematology patients be nurse led?	11.7
64	Do haematology patients with malignant disease get sufficient specialist nurse support?	7.8
72	Role of the nurse consultant in haemato-oncology	5.8
107	Nurses undertaking bone marrow aspiration - will it improve patient experience?	5.8
13	Critical care skills are they an essential requirement for haematology/BMT nurses?	4.9
28	How effective is the CNS role in haemato-oncology?	4.9
85	Nurses' role in care of haemato-oncology patient in BMT workup	3.9
123	What access do patients in the UK have to a CNS?	1.9

Appendix 13:
Top 3 Most Highly Rated First, Second and Third Priorities in Each Category

Appendix 13: Top 3, Most Highly Rated First, Second and Third Priorities in Each Category

Category	1st Priority	%	2nd Priority	%	3rd Priority	%
Education	What is nurses' knowledge of neutropenic sepsis?	28.2	How can chemotherapy training & administration be standardised throughout the UK?	17.5	What is nurses' knowledge of neutropenic sepsis?	14.6
	How can chemotherapy training & administration be standardised throughout the UK?	20.4	How can high standards /levels of knowledge in cytotoxic administration be maintained?	15.5	How can chemotherapy training & administration be standardised throughout the UK?	9.7
	Is depth of knowledge of nurses administering chemotherapy sufficient?	9.7	Is depth of knowledge of nurses administering chemotherapy sufficient?	13.6	Is depth of knowledge of nurses administering chemotherapy sufficient?	8.7
					How can high standards/levels of knowledge in cytotoxic administration be maintained?	8.7
					Educational needs of nurses at 3 levels novice, developing practice, expert	8.7
Service Delivery and Organisation of Care	What is the effect of staffing levels & skill mix on outcomes of care?	16.5	What is the effect of staffing levels & skill mix on outcomes of care?	21.4	Are staff shortages detrimental to practical/emotional support	9.7
	Are staff shortages detrimental to practical/emotional support	16.5	Are staff shortages detrimental to practical/ emotional support	9.7	What is the effect of staffing levels & skill mix on outcomes of care?	8. 7
	Transition from curative to palliative care & treatment	14.6	What impact do different chemotherapy regimes have on nurse workload?	9.7	What impact do different chemotherapy regimes have on nurse workload?	6.8

Appendix 13 continued: Top 3, Most Highly Rated First, Second and Third Priorities in Each Category

Category	1st Priority	%	2nd Priority	%	3rd Priority	%
Effects of Role on Nurses' Health and Support Needs	Long-term health risks of nurses exposed to chemotherapy/ antibiotics	44.7	Psychological effects on health care professionals working in BMT/ haematology	21.4	Availability of training and support and effects on stress development	25.2
	What are the psychological support needs of nurses & other health care professionals?	14.6	What are the psychological support needs of nurses & other health care professionals?	20.4	What are the psychological support needs of nurses & other health care professionals?	17.5
	Is effective clinical supervision available to nurses in haemato-oncology?	13.6	Is effective clinical supervision available to nurses in haemato-oncology?	17.5	Psychological effects on health care professionals working in BMT/ haematology	11.7
Communication/ Patient Information and Education	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	46.6	Effect of communication good/bad on patients	18.4	Timeliness/quality/amount of information at diagnosis and relapse	14.6
	Effect of communication good/bad on patients.	11.7	Patients & relatives views on the information and support they receive regarding diagnosis and treatments	17.5	Effect of communication good/bad on patients	13.6
	Breaking bad news. Who does the patient prefer nurses or doctors?	7.8	Education and pre-assessment of patients having chemotherapy	13.6	Education and pre-assessment of patients having chemotherapy	10.7
					What information do patients require on specific aspects of care?	10.7
Ethical Decision Making	Making decision when active treatment ends and palliative treatment begins	32	When to actively treat and when to withdraw treatment	19.4	How can end of journey decision making with patients be improved?	17.5
	When to actively treat and when to withdraw treatment	21.4	Making decision when active treatment ends and palliative treatment begins	17.5	Does the patient receive sufficient information to provide informed consent?	14.6
	Does the patient receive sufficient information to provide informed consent?	18.4	How can end of journey decision making with patients be improved?	15.5	What is the nurses' advocacy role for haemato-oncology patients?	12.6

Appendix 13 continued: Top 3, Most Highly Rated First, Second and Third Priorities in Each Category

Category	1st Priority	%	2nd Priority	%	3rd Priority	%
Utilising Knowledge and Developing the Evidence Base for Practice	What is best practice in protective isolation care? Is there a best practice?	27.2	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	14.6	Oral care protocol – what's best?	11.7
	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	21.4	What is best practice in protective isolation care? Is there a best practice?	14.6	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	11.7
	Clear guidelines on mucositis management	11.7	Develop evidence base of optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	9.7	What is best practice in protective isolation care? Is there a best practice?	8.7
			Clear guidelines on mucositis management	9.7	Treatment safety including blood	8.7
Nursing Interventions and Care	Management and care of neutropenic patients	46.6	How can prevention of infection measures be improved?	16.5	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	14.6
	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	9.7	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	12.6	What is the role of alternative therapies?	10.7
	How can prevention of infection measures be improved?	9.7	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	12.6	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	9.7
Symptom Management	How can the side-effects of chemotherapy be reduced?	50.5	Disease & treatment related fatigue	26.2	Disease & treatment related fatigue	21.4
	Disease and treatment related fatigue	18.4	How can the side-effects of chemotherapy be reduced?	18.4	Is pain control during bone marrow biopsies effective?	17.5
	Management of GVHD treatment complications	8.7	Management of GVHD treatment complications	16.5	Management of GVHD treatment complications	16.5

Appendix 13 continued: Top 3, Most Highly Rated First, Second and Third Priorities in Each Category

Category	1st Priority	%	2nd Priority	%	3rd Priority	%
Psychosocial Wellbeing and Support	Quality of life- What does it really mean to the patient?	32	What are the psychosocial support needs of patients with haematological cancers & their families?	12.6	How could nurses improve support for patients?	10.7
	What are the psychosocial support needs of patients with haematological cancers & their families?	12.6	Should a psychologist/ counsellor be involved at ward level for patients and relatives?	11.7	What are the psychosocial support needs of patients with haematological cancers & their families?	9.7
	How could nurses improve support for patients?	8.7	Are sexuality issues addressed?	8.7	Should a psychologist/ counsellor be involved at ward level for patients and relatives?	8.7
					Psychological effects of haematological cancers	8.7
Patient and Family Experience	What do patients expect/require from nurses	28.2	What do patients expect/require from nurses?	12.6	How important to patients is access to a CNS?	11.7
	How important to patients is access to a CNS?	8.7	Psychological effects of relapse for the patient & family	8.7	Patient experiences of symptom control	6.8
	Effect of low staff morale and staffing on experiences of isolated patient	7.8	Effect of low staff morale and staffing on experiences of isolated patient	7.8	What effect does a palliative prognosis have on the patient?	6.8
	Psychological effects of intensive treatment on patients & families	7.8			Support of carers	6.8
Nurses' Role	How effective/successful are nurse led services?	29.1	How effective is the CNS role in haemato-oncology?	15.5	Career development for haemato-oncology nurses	14.6
	Critical care skills are they an essential requirement for haematology/BMT nurses?	18.4	Critical care skills are they an essential requirement for haematology/BMT nurses?	13.6	How effective/successful are nurse led services?	12.6
	Do haematology patients with malignant disease get sufficient specialist nurse support?	12.6	Minimum skills/requirements for UK haematology nurses researchers/ managers	13.6	Minimum skills/requirements for UK haematology nurses/ researchers/ managers	12.6
					Development of extended role for nurses in haemato-oncology	12.6

Appendix 14:
Overall Ranks in Categories Rounds 2 and 3

Rank in category round 2	Overall Priorities Round 3 Education	%
1	What is nurses' knowledge of neutropenic sepsis?	55
3	How can chemotherapy training and administration be standardised throughout the UK?	48
7	Is depth of knowledge of nurses administering chemotherapy sufficient?	33
4	How can high standards/levels of knowledge in cytotoxic administration be maintained?	32
2	Access to haematological nurse education/courses	22
12	Educating general nurses of importance of haematology	20
9	Educational needs of nurses at 3 levels novice, developing practice, expert	18
4	What is nurses' awareness of transfusion reactions?	17
6	Are safety precautions in the administration of cytotoxic drugs safe enough?	17
12	What is the impact of specialist education?	11
10	Training of specialist nurses	10
8	What is nurses' awareness of drug related toxicity?	7
11	What is nurses' awareness of viral complications post-BMT/PBSCT?	7
14	Support/training of research nurses	2
15	Training on non-clinical issues eg benefits?	2

Rank in category round 2	Service Delivery and Organisation of Care	%
2	What is the effect of staffing levels and skill mix on outcomes of care?	47
1	Are staff shortages detrimental to practical/emotional support?	37
3	Transition from curative to palliative care & treatment	27
14	Is there a difference in care given in cancer centres and District General Hospitals?	21
11	What impact do different chemotherapy regimes have on nurse workload?	20
4	What are the benefits and limitations of increased outpatient and home care?	18
7	Safety of care when haematology combined with another speciality	18
14	Blood product replacement - are we over transfusing?	15
9	How can continuity of care be improved?	10
14	Recruitment and retention of all grades haematology/BMT nurses	9
5	Are patient outcomes improved through multi-disciplinary team working?	9
21	Issues in shared care - is it effective?	7
5	Are palliative care needs being addressed?	8
8	Palliative care - when should it be initiated?	7
9	Improving services at home eg patient involvement and treatment options	7
17	Does senior staff ratio ie sisters and above improve patient care?	7
26	How can staff be effectively rotated through a cancer network?	7
23	Should haematology be separate from oncology?	6
22	Impact of the inevitable reduction of blood donors for haematology patients	5
11	Consistency of practice between palliative care and haematology	5
19	Does collaboration exist in haematology between drs and nurses?	5
16	How can better links with palliative care services be facilitated?	4
20	Lack of specialist care in rural communities	4
27	Do we overuse blood tests? Especially in lymphoma	3
24	Gaining enthusiasm from health professionals for clinical trials/research	1
22	Impact of National Institute of Clinical Excellence (NICE) guidelines on nursing hours	0
25	When is appropriate time to refer to Macmillan services?	0

Rank in category round 2	Effects of Role on Nurses' Health and Support Needs	%
1	Long-term health risks of nurses exposed to chemotherapy/antibiotics	68
3	What are the psychological support needs of nurses & other health care professionals?	53
2	Psychological effects on health care professionals working in BMT/haematology	45
4	Is effective clinical supervision available to nurses in haemato-oncology?	43
8	Availability of training and support and effects on stress development	36
7	How staff feel about the workplace	23
4	Staff support and counselling	22
6	Does BMT burnout in nurses exist today?	15

Rank in category round 2	Communication/Patient Information and Education	%
1	Patients' and relatives' views on the information and support they receive regarding diagnosis and treatments	73
2	Effect of communication good/bad on patients	44
4	Timeliness/quality/amount of information at diagnosis and relapse	30
5	Education and pre-assessment of patients having chemotherapy	29
8	Breaking bad news. Who does the patient prefer nurses or drs?	26
9	Is time available to identify patient concerns?	23
7	What information do patients require on specific aspects of care?	22
6	Information giving and patient empowerment	21
2	Provision of information for children of adults with a haematological cancer	16
19	Nurses' reactions to dealing with emotional questions	15
11	Patients' and carers' education on physical aspects of care	5

Rank in category round 2	Ethical Decision Making	%
1	Making decision when active treatment ends and palliative treatment begins	61
2	When to actively treat and when to withdraw treatment	49
3	Does the patient receive sufficient information to provide informed patient consent?	47
5	How can end of journey decision making with patients be improved?	39
5	What is the nurses' advocacy role for haemato-oncology patients?	26
7	Appropriate use of blood transfusion in haematological palliative care	24
4	Truth telling in BMT/PBSCT	18
8	How do patients make decisions about clinical trials at diagnosis?	13
9	Ethical issues of treatment of the elderly	13
11	How can patients have more autonomy?	7
12	Ethical issues related to DNA technologies	4
10	How can informed consent be ensured if the patient is incapacitated?	2

Rank in category round 2	Utilising Knowledge and Developing the Evidence Base for Practice	%
1	What is best practice in protective isolation care? Is there a best practice?	51
3	National guidelines/standards of care for central venous catheters including dressings, cleaning and flushing	48
1	Clear guidelines on mucositis management	31
4	Develop evidence base for optimal care/use/problem solving of central venous catheters including reducing infection/preventing thrombosis	26
4	Oral care protocol - what's best?	22
7	Development of evidence base for optimal control of nausea & vomiting	18
6	How can clinical research be implemented into practice?	15
12	What is best practice for nursing management of day care patients?	15
15	Department of Health Improving Outcomes Guidelines are they making a difference?	15
9	Implementing an effective audit tool to monitor Hickman line care	12
8	Treatment safety including blood	12
10	How can the risk/incidence of chemotherapy extravasation in a peripheral line be reduced?	9
14	What nursing theory should underpin haematology nursing practice?	9
10	What are the most effective mouthwashes during chemotherapy?	7
12	Safety issues related to nebulised pentamidine administration	6
15	Prevention of reactions to blood/platelet transfusions	5

Rank in category round 2	Nursing Interventions and Care	%
1	Management and care of neutropenic patients	65
3	Are antimicrobial diets/clean food regimes beneficial in neutropenia?	38
2	How can prevention of infection measures be improved?	36
5	Long-term follow up/rehabilitation for patients with haematological cancers	29
3	Nutritional support for patients undergoing transplant procedures and high dose chemotherapy	27
6	Are fertility issues addressed?	19
8	Venous access assessment in ensuring correct device used	14
13	What is the role of alternative therapies?	14
11	Central venous catheters - do risks outweigh the benefits?	14
6	How can needs of older inpatients with myeloma & CLL be best met?	13
9	Dealing with relatively young patients	13
14	Exercise and fitness during and after transplant	8
9	Immediate care post-BMT	6
12	Pre-BMT care	6

Rank in category round 2	Symptom Management	%
1	How can the side-effects of chemotherapy be reduced?	78
2	Disease and treatment related fatigue	65
3	Management of GVHD treatment complications	43
5	Is pain control during bone marrow biopsies effective?	36
8	Elimination problems due to treatment	26
4	Control of gastric symptoms during allogeneic BMT	23
9	Alopecia	16
7	Management of veno-occlusive crisis	10
6	Skin care post allogeneic BMT	6

Rank in category round 2	Psychosocial Wellbeing and Support	%
1	Quality of life - What does it really mean to the patient?	44
3	What are the psychosocial support needs of patients with haematological cancers and their families?	36
2	How could nurses improve support for patients?	25
8	Should a psychologist/counsellor be involved at ward level for patients & relatives?	25
5	Psychological effects of haematological cancers	21
4	Long-term survival anxiety when returning to clinic for follow up	20
8	What are the effects of surviving long term?	17
15	Are sexuality issues addressed?	17
18	How do patients cope with fatigue?	15
7	What is the value of counselling for BMT patients pre & post transplant?	11
11	What are the short and long term psychological effects of isolation?	10
13	What effect do haematological cancers have on mood/personality?	8
21	Ongoing psychological care from hospital to home	8
5	What is the psychological impact of BMT?	7
13	What short and long term psychosocial coping strategies do patients use?	7
23	Cultural issues	7
13	What is the correlation between myelosuppression and depression for the isolated patient?	6
16	What is the extent/impact of sexual dysfunction?	6
20	Spirituality	5
24	Mental illness in BMT	5
19	Measure psychological interventions for haematology patients	4
17	Should specific criteria be used for pre-transplant psychological assessment?	2
22	What difficulties do patients have with compliance in taking long-term medication?	1
25	Role of hypnotherapy & psychoneuroimmunology	1
10	What are the psychological needs of the older haematology patient?	0

Rank in category round 2	Patient and Family Experience	%
1	What do patients expect/require from nurses?	46
6	How important to patients is access to a CNS?	26
3	Effect of low staff morale and staffing on experiences of isolated patient	21
2	Psychological effects of relapse for the patient & family	21
13	What are the short and long term side-effects of GCSF on donors?	18
4	What effect does a palliative prognosis have on the patient?	16
5	Patient experiences of symptom control	15
10	Psychological effects of intensive treatment on patients & families	15
18	How do patients perceive the role of nurse specialist?	12
8	Effects of illness on family especially spouse/partner?	12
8	How can patient experience of diagnosis and follow up be improved?	11
20	What are the psychological issues for sibling donors?	11
7	Impact of haematological cancer on family dynamics/relationships	10
13	Patients' views of where they are treated	9
15	Patient experience of current care	8
25	Support of carers	8
18	Patient view of the meaning of a cancer diagnosis	7
16	Patient experiences of hospitalisation	7
16	Family support for patients having BMT/lengthy chemotherapy	6
23	Impact of myeloproliferative disorders on lives	6
13	What is the lived experience of receiving diagnosis/achieving remission?	5
26	What is the donor experience?	5
22	Experiences of patients with failed stem cell harvest	3
29	Haematology patients' views on admission to an intensive care unit	3
10	Spouse/significant others' experiences and supportive role	2
23	Relatives' role in nursing an oncology patient	2
21	Lack of psychosocial care for patients and families	2
28	What do patients perceive as the benefits of having a bone marrow transplant?	2
26	Nurses' role in supporting the donor	1

Rank in category round 2	Nurses' Role	%
1	How effective/successful are nurse-led services?	55
2	Critical care skills are they an essential requirement for haematology/BMT nurses?	37
3	Minimum skills/requirements for UK haematology nurses/researchers/managers	34
7	Do haematology patients with malignant disease get sufficient specialist nurse support?	29
4	How effective is the CNS role in haemato-oncology?	29
4	Development of extended role for nurses in haemato-oncology	29
9	Should follow up of haematology patients be nurse led?	27
6	Career development for haemato-oncology nurses	26
11	Nurses undertaking bone marrow aspiration - will it improve patient experience?	16
8	Role of the nurse consultant in haemato-oncology	10
12	What access do patients in the UK have to a CNS?	6
9	Nurses' role in care of haemato-oncology patient in BMT workup	6