This electronic thesis or dissertation has been downloaded from the King's Research Portal at https://kclpure.kcl.ac.uk/portal/

Understanding the dilemmas inherent in the communication between clinicians, patients and carers about neutropenic sepsis
a grounded theory study

Oakley, Catherine Mary

Awarding institution:
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

END USER LICENCE AGREEMENT

Unless another licence is stated on the immediately following page this work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International licence. https://creativecommons.org/licenses/by-nc-nd/4.0/

You are free to copy, distribute and transmit the work

Under the following conditions:

- Attribution: You must attribute the work in the manner specified by the author (but not in any way that suggests that they endorse you or your use of the work).
- Non Commercial: You may not use this work for commercial purposes.
- No Derivative Works - You may not alter, transform, or build upon this work.

Any of these conditions can be waived if you receive permission from the author. Your fair dealings and other rights are in no way affected by the above.

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 15. Jan. 2025

Understanding the dilemmas inherent in the communication between clinicians, patients and carers about neutropenic sepsis: A grounded theory study

A thesis submitted for the Doctorate in Philosophy in Nursing Research

King's College London

Catherine Oakley

March 2015

Abstract

Cancer chemotherapy can reduce immunity. The lowered immune response increases the risk of infection that can develop into a life threatening secondary complication called neutropenic sepsis. The neutropenic sepsis causes a significant number of hospital admissions and an estimated 700 deaths within the United Kingdom (UK) each year. Delays in patients reporting symptoms of neutropenic sepsis may exacerbate the problem, causing longer and more costly hospital stays and a greater risk of death. Furthermore, chemotherapy treatment may also be delayed, which may affect prognosis.

This study took an ethnographic and constructivist grounded theory approach to develop a theory to explain why patients delay presenting to hospital with neutropenic sepsis. A longitudinal element of the study involved non-participant observation of women with breast cancer being provided with information about neutropenic sepsis by oncology doctors and chemotherapy nurses. Interviews were carried out, with observed patients following the observation and at the end of treatment. A retrospective element involved interviews with women with breast cancer who had developed neutropenic sepsis, their carers and doctors and nurses who worked within oncology and Accident and Emergency (A&E) departments. Analyses commenced with the earliest data gathered and a rich theoretical picture was built through comparing perspectives, pursuing areas of inquiry and recruiting particular participants who became of interest to the developing theory.

A grounded theory evolved, which suggests patients may delay presenting to hospital with neutropenic sepsis because the seriousness of it is underplayed by clinicians, patients and their carers. Findings of this study have immediate implications for clinical practice to ensure patients and their carers are adequately supported by clinicians to understand the seriousness and be equipped to identify and report neutropenic sepsis. Furthermore, study findings should inform the design of future research to develop interventions, to promote earlier recognition and treatment for this important chemotherapy complication.

Acknowledgments

Many people have supported me to develop this thesis. I would like to thank my supervisors; Professor Alison Metcalfe, Doctor Cath Taylor and Professor Emma Ream for believing in me and for gently and expertly guiding me through the process. Thank you also to Guys and St Thomas' NHS Foundation Trust (especially Mairead Griffin) who importantly gave me the time and support to undertake my doctoral studies. I also thank the National Institute for Health Research (NIHR) for funding the training fellowship that enabled me to carry out this research. I am privileged to have met Juliette Corbin, an international expert in grounded theory at an inspirational grounded theory summer school in Italy in 2012. I thank Juliette for our Skype calls where we discussed my application of the grounded theory methodology and the emerging theory.

I also thank my partner Errol Holness and Marianne Beck, David Beck, Felicity Oakley and Doctor Janine Mansi for their patience and support during the time I have worked on this thesis. Finally, I thank the patients, carers, doctors and nurses who gave their time and honest accounts of their experiences which I hope I have justly represented within this thesis.

This work is produced by Catherine Oakley under the terms of the doctoral research training fellowship issued by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the author and not necessarily those of the NHS, the NIHR or NHS England.

Contents

List of tables

List of figures

Glossary of terms

Carers

Carers who participated in the study, were identified by participating patients, as the relative or friend who provided them with most support during chemotherapy treatment.

Chemotherapy

For this study, chemotherapy drugs are defined as cytotoxics, that destroy rapidly dividing cancer cells and that also cause damage to rapidly dividing normal cells that usually recover.

Clinicians

Clinicians who took part in the study were doctors and specialist nurses, who worked with patients in relation to chemotherapy consent, information and support. Participating clinicians worked within oncology and accident and emergency departments.

Neutropenic Sepsis

Definition of neutropenia and fever

Diagnose neutropenic sepsis in patients having anticancer treatment whose neutrophil count is 0.5 x 10^9 per litre or lower and who have either:

– a temperature higher than 38°C **or**

– other signs or symptoms consistent with clinically significant sepsis

(National Institute of Clinical Excellence (NICE), 2012, p.vi)

Patients

Patients who participated in this study were women aged over 18 years, with a diagnosis of breast cancer and prescribed chemotherapy with a risk of causing neutropenic sepsis. They spoke English and were considered by clinicians as physically and emotionally able to participate.

Patient-Centred Communication in Cancer Model

A framework developed by the National Cancer Institute in America. This is based upon mediating and moderating influences of communication between clinicians, patients and carers that may affect patient health-related outcomes including quality of life and survival.

Abbreviations

Absolute Neutrophil Count (ANC)

Accident and Emergency (A&E)

American Society of Clinical Oncology (ASCO)

Critical Appraisal Skills Programme (CASP)

The Common Terminology Criteria for Adverse Events (CTCAE)

European Organisation for Research and Treatment of Cancer (EORTC)

General Practitioner (GP)

Growth Colony Stimulating Factor (G-CSF)

Medical Subject Headings (MeSH)

National Cancer Institute (NCI)

National Chemotherapy Advisory Group (NCAG)

National Comprehensive Cancer Network (NCCN)

National Confidential Enquiry into Patient Outcomes and Death (NCEPOD)

National Institute of Clinical Excellence (NICE)

National Institute for Health Research (NIHR)

Multinational Association of Supportive Care in Cancer (MASCC)

Patient Care Monitor Neutropenia Index (PCM-N)

Patient-Centred Communication in Cancer Model (PCC)

Research and Development (R&D)

Research Ethics Committee (REC)

Systemic Anti-Cancer Treatment (SACT)

United Kingdom (UK)

United States of America (USA)

Chapter One: Introduction

1.1 Introduction

Over 331,000 people are diagnosed with cancer each year within the United Kingdom (UK) (Cancer Research UK. *Cancer incidence statistics*. [ONLINE] Available at: http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/. [Accessed 28 January 14] an increasing number of whom are treated with chemotherapy. Between 2002/03 and 2006/07, it is estimated that programmes of chemotherapy prescribed in the UK rose from 40,000 to 65,000 per annum (National Chemotherapy Advisory Group (NCAG), 2009).

Chemotherapy involves the administration of drugs to destroy rapidly dividing cancer cells. Intended benefits of chemotherapy are:

- Curative treatment.
- Palliation, to control or reduce the size of the cancer. To improve quality of life and survival.
- Adjuvant treatment, following surgery to reduce the risk of recurrence.
- Neo-adjuvant treatment, to reduce the size of the cancer before surgery.

The most common routes for chemotherapy drug administration are intravenous and oral. Drug delivery typically occurs in three to four weekly cycles over many months to make up a treatment programme. Within the UK the majority of chemotherapy is delivered within the outpatient setting. Patients undergoing chemotherapy treatment typically receive intravenous drugs in the hospital. Where oral chemotherapy is prescribed this is self-administered at home.

Chemotherapy drugs unfortunately cause side effects, mainly because they destroy healthy as well as rapidly dividing cancer cells. The challenge for prescribers of chemotherapy is to balance the delivery of drugs at the optimal dose, to improve outcome, whilst minimising toxicity. The type and severity of chemotherapy side effects depend on the chemotherapy drug or combination of drugs administered and the variation in patients' responses to medication.

Common complications of chemotherapy such as nausea and vomiting, mucositis, alopecia, diarrhoea, fatigue, weakness, hair loss, peripheral neuropathy, muscle and joint pain, are usually well managed. However, patients can still become extremely debilitated by chemotherapy side effects and are at risk of developing bone marrow suppression. Of concern is the ability of some chemotherapy drugs to cause a reduction in neutrophils, which are a type of white blood cell formed and inactive within the bone marrow and required by the body for first line immune defence. Neutrophils take about six days to enter the blood stream (Dancey et al., 1976), where they circulate for between eight hours and five days (Pillay et al., 2010). Neutrophils respond to early signals from the body that infection or injury are present and migrate to kill cells, such as bacteria that might cause infection. This is achieved, either through direct attack or by triggering other immune responses such as T cell activation (Nathan, 2006). A low neutrophil count means the body's ability to fight infections is compromised. There is then an associated risk of infections quickly developing to septicaemia, which may progress to organ failure and death (Kurtz et al., 2006). Septicaemia, under these circumstances, is often referred to as neutropenic sepsis.

The National Institute of Clinical Excellence (NICE) have produced clinical guidance on the prevention and management of neutropenic sepsis in cancer patients. NICE estimate around two patients die from neutropenic sepsis every day in the UK, which may be a conservative estimate (NICE, 2012). Neutropenic sepsis can be effectively treated with intravenous antibiotics. The earlier patients present to hospital with it, the better the outcomes in terms of survival and reduced debilitation from sepsis.

A concern within my clinical practice related to a common behaviour, where patients delayed reporting symptoms of neutropenic sepsis that they developed following chemotherapy treatments. This behaviour occurred, despite my clinical colleagues and I, believing we clearly informed patients and their carers about neutropenic sepsis, and of the symptoms they should monitor, and report, to dedicated 24-hour helplines. Despite serious concerns about late patient presentation to hospital with neutropenic sepsis, there is a lack of research to explore why this occurs. The purpose of this study therefore is to better understand this phenomenon.

This study was conducted between November 2011 and February 2013 within a London Cancer Centre. The research design consisted of an ethnographic approach for data collection.

Constructivist grounded theory was applied to direct data collection and the analysis. A grounded theory research design was chosen, to enable development of a theory, to explain the likely complexities underpinning delayed patient presentation to hospital with neutropenic sepsis that could emerge from and be grounded in the data. This evidence is required to reduce avoidable delays in presentation through changes in clinical practice and introduction of interventions to enhance patient self-management.

Chapter Two: Scoping literature review

2.1 Introduction

An initial search of the literature did not identify any studies that specifically explored communication of risks of neutropenic sepsis to patients undergoing chemotherapy for cancer, or reasons they may delay presenting to hospital when this occurs. This initial review did identify a large body of literature focused on neutropenic sepsis more generally. Given the breadth of the literature and lack of suitability of this for a systematic review, a scoping review (Arksey and O'Malley, 2005, Gough et al., 2012, Norman and Griffiths, 2014) was carried out, to identify and describe evidence relevant to the research questions addressed by this thesis. The methods for this scoping review followed five stages, as outlined by (Arksey and O'Malley, (2005):

Stage one:	Identifying the review question
Stage two:	Identifying potentially relevant papers
Stage three:	Selecting papers for inclusion
Stage four:	Charting the data
Stage five:	Collating, summarising and reporting the results

2.1.1 Stage one: Identifying the review question

The intention of the scoping review was to set the context for the study reported within this thesis. The review question was:

What is known within existing literature about neutropenic sepsis, the risks of this to patients, the reasons for delayed presentation and good practice in relation to communicating risks?

2.1.2 Stage two: Identifying potentially relevant papers

The initial search indicated that very little evidence existed about why patients delay reporting neutropenic sepsis. Consequently, a search strategy was designed based up on a combination of searching electronic databases and augmenting. The later stage (augmenting) included: citation searching; hand searching of relevant journals and expert knowledge of existing data sources, including papers, guidelines, reports and websites. Stage one of the search strategy involved a search of relevant bibliographic databases to capture published evidence. Searched databases included: British Nursing Index, CINHAL, the Cochrane Database of Systematic Reviews, Embase, MEDLINE and PsycInfo. Four key concepts emerged from the review research question: cancer, chemotherapy, neutropenic sepsis and patient education. Mesh headings and keywords associated with each of the four concepts were identified and adapted according to various database conceptual frameworks, as demonstrated within table 2.1. These were then combined within concepts and between concepts using Boolean indicators (AND, OR, NOT) to focus the searches.

Table 2.1.Search terms applied to Ovid MEDLINE

	Cancer AND /OR Chemotherapy AND Neutropenic Sepsis		
MeSH Heading	Neoplasm	Antineoplastic agents	Chemotherapy induced neutropenia OR Febrile neutropenia OR neutropenia OR Sepsis
Key Word		Chemotherapy	
	AND Patient Education		
MeSH Heading	Patient Education		

Many papers that reported neutropenic sepsis data did not immediately appear relevant to the scoping review question. However, reading of this more general literature identified data that were pertinent.

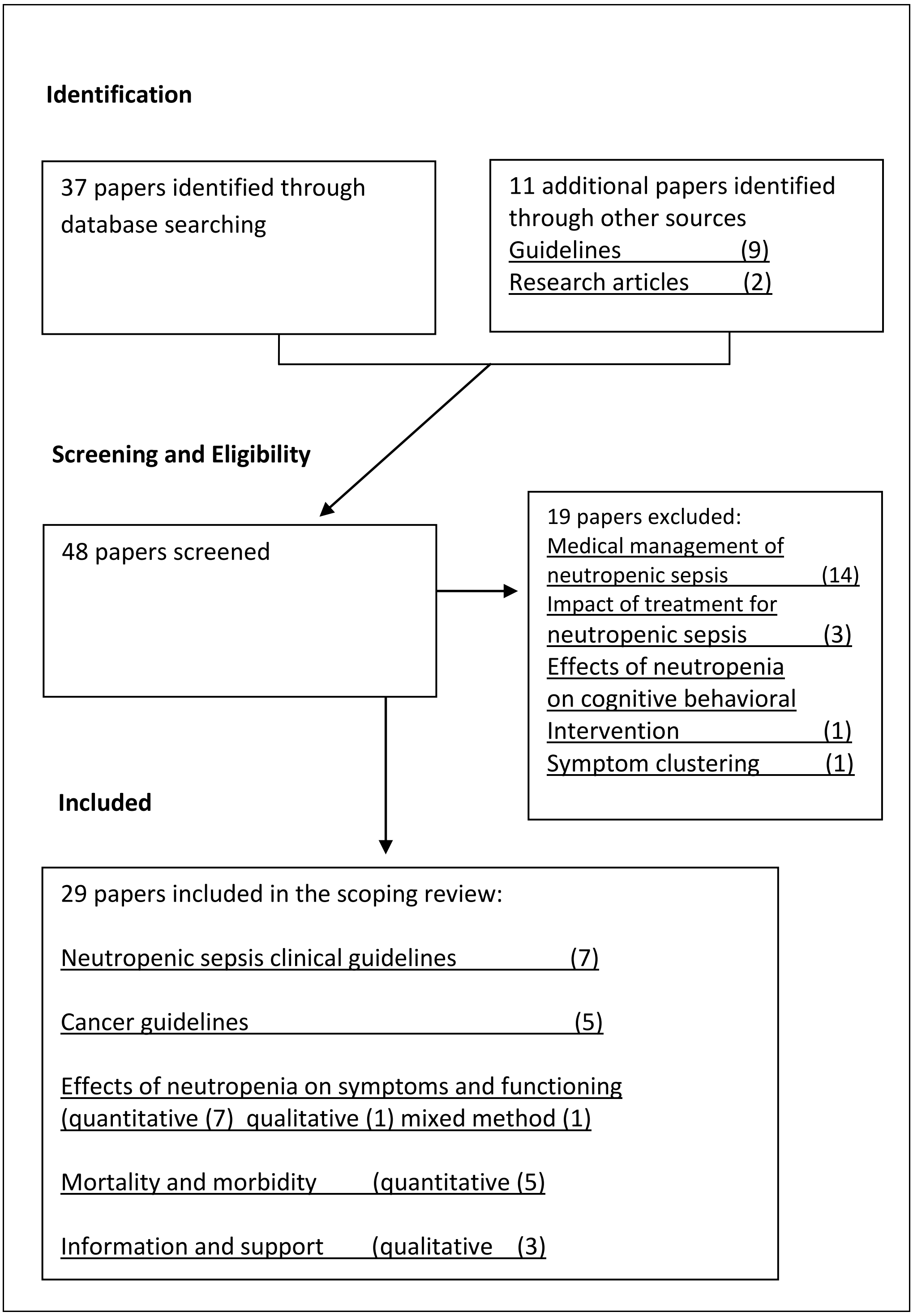
Stage two of the search strategy (augmenting) included citation searching, hand searching, and expert knowledge of data sources including websites, papers, reports and guidelines. Citation searching included manual searches of reference lists in identified articles to reveal further relevant papers. Citation searching also included a review of papers that cited the original article of interest. Pertinent cancer journals, that were hand searched for appropriate articles, included: Oncology Nursing Forum; Supportive Cancer Care; Cancer Nursing; the British Journal of Cancer and the European Journal of Cancer Care. Websites reviewed, included those which had produced guidelines important to the management of neutropenic sepsis: NICE, the Department of Health, the American Society of Clinical Oncology (ASCO), the European Organisation for Research and Treatment of Cancer (EORTC) and The UK Sepsis Campaign. Further websites searched included The Oncology Nursing Society and the Multinational Association of Supportive Cancer Care (MASCC), both of which have online neutropenic sepsis forums for clinicians, and Macmillan Cancer Support, which produces information about chemotherapy for patients and others affected by cancer.

2.1.3 Stage three: Selecting papers for inclusion

Papers that included a focus on chemotherapy induced neutropenia in adult cancer patients were included. Articles reporting neutropenia in non-cancer and paediatric populations and those not available in English language were excluded from the review. The selection process (figure 2.1) was adapted from PRISMA guidance (Moher et al., 2009) developed to conduct systematic reviews. An initial 37 papers were identified through database searching. A further 11 were identified through other sources. All identified papers were read and 19 were rejected, due to these not answering the review question. Of those rejected, fourteen related to medical management of neutropenic sepsis; three focused on the effects of treatment of neutropenic sepsis on patients and carers; one mentions neutropenia to have a moderating impact on a cognitive behavioural intervention, designed to reduce chemotherapy symptoms. This did not provide data about patient identification and reporting of neutropenic sepsis. One paper referred to chemotherapy symptom clustering, but did not relate this to symptoms of neutropenic sepsis. Twenty nine papers were included in the literature analysis. The papers were produced from a range of countries: USA, (12); UK (10); Europe (3); Multinational (2); Australia (1); and Pakistan (1). The reasons for inclusion are summarised in figure 2.1.

Figure 2.1. **Process of information gathering.**
Adapted from PRISMA (Moher et al., 2009); p334

For permission see appendix 2



2.1.4 Stage four: Charting the data

Core information from each paper included in the scoping review was charted. This included the country of origin, study population, aims of the study, methodology, outcome measures and findings. All included papers were read and the focus of each paper was examined to identify the aspects of the overall review question addressed by each paper. This resulted in the identification of four main themes covered by the papers (each paper may cover one or more themes):

1. Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer.
2. Symptoms of neutropenic sepsis that patients should report to clinicians.
3. Knowledge about delayed patient presentation to hospital with neutropenic sepsis.
4. Education of patients about neutropenic sepsis.

Findings from each paper were then mapped to each of these themes. Mapped data were compared, contrasted and drawn upon, to describe evidence in relation to each the four themes. It was envisaged that the first three themes would provide information useful for educating patients and carers about recognising neutropenic sepsis symptoms. Theme four would describe optimal strategies for clinicians to educate patients about neutropenic sepsis and associated risks. Superscript numbers that relate to the themes (1-4) are applied to the scoping review question to demonstrate the applicability of the mapped data:

What is known within existing literature about neutropenic sepsis, the risks of this to patients $^{\text{(themes 1, 2)}}$ *the reasons for delayed presentation* $^{\text{(theme 3)}}$ *and good practice in relation to communicating risks* $^{\text{(theme 4)}}$

Papers that are included in the scoping review are summarised within table 2.2. Detail is provided about the: types of papers / methods employed; findings that are related to the scoping review question (the four themes) and the quality of the evidence described. The quality rating approach will be described within the next stage (stage five: collating, summarising and reporting the results). A more in-depth summary of these papers may be found at appendix 1.

Table 2.2 Scoping review: Characteristics of included papers

Reference	Type of paper / method	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Neutropenic sepsis clinical guidelines			
US Department of Health and Human Sciences, (2009)	Literature review	Suspect sepsis if temperature 38.3°C, or 38°C for more than one hour. (1)	High
Dellinger et al., (2012)	Literature review	Intravenous broad spectrum antimicrobials should be administered within one hour of sepsis recognition. (1)	High
NICE, (2012)	Systematic literature review	Suspect NS if temperature >38°C, or clinical signs of sepsis (1) (low quality evidence). Intravenous antibiotics within one hour (1) (high quality evidence). Poor prognosis with: mucositis, temperature >39°C, clinical signs of infection, chills, confusion (1) (low quality evidence). Early symptoms of NS (2) and patient education for NS (4) (low quality evidence).	High
The UK Sepsis Trust, (2013)	Literature review	Symptoms of severe sepsis (1) (see table 2.8). Intravenous antibiotics and fluids within one hour. (1)	High
Aapro et al., (2006; 2011) (EORTC)	Systematic literature review	High risk indices for NS: chemotherapy regimens with > 20% risk of causing neutropenia, age ≥65 years, advanced disease, no antibiotic prophylaxis. (1)	High
Klastersky et al., (2000) (MASCC)	Quantitative	High risk of complications from NS: age >60 years, haematological malignancy and co-morbidities. (1)	High
Smith et al., (2006) (ASCO)	Literature review	High risk indices for NS: chemotherapy regimens with high (>20%) risk of causing neutropenia, age>65years, advanced disease, co-morbidities. (1)	High

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** ASCO (American Society of Clinical Oncology); CTCAE (Common Terminology Criteria for Adverse Events); EORTC (European Organisation for Research and Treatment of Cancer); GRADE (Grading of Recommendations, Assessment Development and Evaluation); MASCC (Multinational Association for Supportive Care in Cancer); NICE (National Institute of Clinical Excellence); NS (Neutropenic Sepsis).

Table 2.2 continued:

Reference	Type of paper / method	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Cancer guidelines			
NCEPOD, (2008)	Mixed method	Poor clinical practice in relation to neutropenia. (1) Patients delayed presentation with NS symptoms by ≥24-hours, (may increase mortality risk). (1)	Medium
NCAG, (2009)	Expert opinion	Patient education should be improved. (4) 24-hour on-call services should be provided for patients during chemotherapy. (4)	Low
Royal College of Physicians, (2012)	Patient experience survey	Over half of admissions associated with feeling unwell or fever. (1) Some patients delayed presenting with NS for ≥2days. (3)	Medium
National Cancer Peer Review, (2011)	Expert opinion	Expect 24-hour on-call services to be in place for cancer patients during chemotherapy. (4)	Low
National Cancer Peer Review, (2013)	Expert opinion	Require emergency cancer services to be in place. (4)	Low
Primary Research: Effects of neutropenia on symptoms and functioning			
Fortner et al., (2005a)	Quantitative.	Reduced physical and social functioning in grade 4 compared to grades 0-3. (2)	Low
Fortner et al., (2006)	Quantitative	Reduced physical and social functioning in grades 3 - 4 compared with grades 0 – 2. (2)	Low
Fortner et al., (2005b)	Qualitative	Reduced physical and social functioning with grade 4 neutropenia. (2)	Low
Fortner and Houts, (2006)	Quantitative	Reduced physical and social functioning in grades 3 - 4 compared with grades 0 – 2. (2)	Low
Nirenberg et al., (2004)	Quantitative	Mucositis present in 37% of cases. (2) Mean delay in presenting 21 hours (range 1-72). (3) Co-morbidities and advanced cancer associated with later presentation. (3)	Low
Wagner et al., (2008)	Quantitative	FACT-N demonstrated reduced physical and social functioning. (2)	Low
Olsen et al., (2011)	Quantitative	PCM-N distinguished between grades 3-4 and 0-2. (2)	Medium
McKenzie et al (2011)	Quantitative	Some patients delayed presenting by 2-7 days. (3)	Low
Higgins and Hill (2012)	Audit	Presenting symptoms: Fever range: < 36° C - 40°C. (2) 34% patients delayed presenting > 24 hours. (3)	Low

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** FACT-N (The Functional Assessment of Cancer Therapy-Neutropenia Instrument); NS (Neutropenic Sepsis); NCAG (National Chemotherapy Advisory Group); NCEPOD (National Confidential Enquiry into Patient Outcomes and Death); PCM-N (Patient Care Monitor Index 1.0 Revised Neutropenia Index).

Table 2.2 continued:

Reference	Type of paper / method	Important Findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Primary Research: Morbidity and mortality associated with neutropenic sepsis			
Okera et al., (2011)	Audit	Risk indices for NS: advanced disease; age>65years; previous neutropenia; no G-CSF or antibiotic; chemotherapy > 20% risk. (1) Mortality 3 (4.2%) (1) Infection symptoms: Respiratory, GI, mucositis. (2)	Low
Kuderer et al., (2006)	Audit	Mortality rate 9.5% (range 0-50%). (1) Risk indices for mortality: Co-morbidities. (1) Cost estimate $1.06 billion. (1)	Low
Chirvella et al., (2009)	Quantitative	Disease free survival is positively affected by reduced chemotherapy treatment delays and maintaining dose intensity. (1).	High
Vincent et al., (2006)	Quantitative	Prognostic variables: Older age and co-morbidities. (1)	High
Malik et al., (2001).	Quantitative	Most patients in shock presented to A&E, were older and had advanced disease. (1) Symptoms of septic shock: diarrhoea; altered mental state; bleeding and dyspnoea. (1) Patients delayed presenting. (3)	Low
Information and support			
Nirenberg et al., (2006b)	Clinical guideline and literature review	Inconsistent guidelines, including symptoms of NS (2). Poor evidence to guide NS education for patients. (4)	Low
Nirenberg et al., (2010)	Survey	Nurse Knowledge and confidence in managing NS increase with greater experience and education. (1) Over half of nurses were unaware that NS is most likely after the first chemotherapy. (4)	Low
Higgins,(2008)	Survey	Most patients had a chemotherapy alert card and kept it with them. Patients felt reassured there was a 24-hour on-call service. (4)	Low
Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis.			

2.1.5 Stage five: Collating, summarising and reporting the results

Scoping reviews do not aim to formally judge the quality of the literature through systematic processes (Arksey and O'Malley, 2005). Design and sampling characteristics of studies cited within this chapter, were reviewed in order to inform judgements about the strength of the evidence and consequent ability to draw conclusions from it (Griffiths et al., 2009). Specifically, the Critical Appraisal Skills Programme (CASP. 2014. [ONLINE] Available at: http://www.caspinternational.org. [Accessed 02 February 2014] tool for reviewing qualitative research (table 2.3) was applied to each identified qualitative study. The Critical Review Form; Quantitative Studies (Law et al., 1998) (table 2.4) was completed for each quantitative research paper due to the range of reviewed study designs and the need for a generic quantitative tool. These tools were used to identify key strengths and limitations of papers. Papers were categorised into high, medium or low quality based upon an overall subjective judgement of the trustworthiness of the findings. Jones et al., (2014) have used this methodology to synthesis finding across multiple design types / source and to take account of quality. Nine studies were considered to be of high quality, three were deemed to be of medium quality and seventeen were considered as low quality (table 2.2).

Table 2.3. **CASP qualitative research checklist (2014)**
For permission see appendix 2

Q1 Was there a clear statement of the aims of the research?
Q2 Was a qualitative methodology appropriate?
Q3 Was the research design appropriate to address the aims of the research?
Q4 Was the recruitment strategy appropriate to the aims of the research?
Q5 Was the data collected in a way that addressed the research issue?
Q6 Has the relationship between researcher and participants been adequately considered?
Q7 Have ethical issues been taken into consideration?
Q8 Was the data analysis sufficiently rigorous?
Q9 Is there a clear statement of the findings?
Q10 How valuable is the research?

Table 2.4. Critical review form quantitative studies (Law et al., 1998)

For permission see appendix 2

STUDY PURPOSE: Was the purpose stated clearly? (Outline the purpose of the study. How does this study apply to research areas and/or your research question?).
LITERATURE: Was relevant background literature reviewed? YES NO (Describe the justification of the need for the study).
DESIGN: Describe the study design. Was the design appropriate for the study question? Specify any bias that may have been operating and the direction of their influence on the results.
SAMPLE: Was the sample described in detail (who; characteristics; how many, how was sampling done?). If more than one group, was there similarity between the groups? Was the sample size justified? Describe ethics procedures. Was informed consent obtained?
OUTCOMES: Specify the frequency of outcome measurement, outcome areas and measures used. Were the outcome measures reliable? Were the outcome measures valid?
INTERVENTION: Provide short description of the intervention. Is the intervention described in detail? Was contamination avoided? Was co-intervention avoided?
RESULTS: Were results reported in terms of statistical significance (what were the results? Were they statistically significant (i.e. $p<0.05$)? If not statistically significant, was the study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis? Were the analysis method(s) appropriate). Was clinical importance reported (What was the clinical importance of the results? Were differences between groups clinically meaningful (if applicable)? Were drop outs reported (Did any participants drop out from the study? Why? Were reasons given and were drop outs handled appropriately?).
CONCLUSIONS AND CLINICAL IMPLICATIONS: Were conclusions appropriate given study methods and results? (What did the study conclude? What are the implications of these results for practice? What are the main limitations or biases in the study?).

Charting the data, required breaking down the review question into its' component parts. Findings from each study that were relevant to the scoping review question were identified and aligned under four overarching themes for reporting the findings. Finally findings from all the included papers were appraised and described, within each of the four themes. This formed a summative understanding of the latest research evidence, pertinent to understand why patients' may delay presenting to hospital with neutropenic sepsis.

2.2 Findings from the scoping review

Analysis and synthesis of the findings and consideration of the strength of these informed the state of the knowledge within each of the four themes.

2.2.1 Theme one: Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer.

2.2.1.1 Defining neutropenic sepsis

Neutropenic sepsis arises from the administration of cancer chemotherapy treatments. Chemotherapy can cause bone marrow suppression, leading to anaemia through lowered haemoglobin production, thrombocytopenia due to reduced platelet production and neutropenia which is a low absolute neutrophil count (ANC). Depending on the chemotherapy drugs and timing of treatment cycles, patients tend to develop neutropenia around 10 to 14 days after chemotherapy has been administered. NICE (2012), within neutropenic sepsis guidance, describes an associated increase in illness and mortality, with declining immunosuppression following chemotherapy, as defined by the absolute neutrophil count.

The stages of neutropenia and neutropenic sepsis are represented within table 2.5 (US Department of Health and Human Sciences, 2009, NICE, 2012, The UK Sepsis Trust, 2013, Dellinger et al., 2013). This supports a distinction required by NICE (2012), between neutropenia (low neutrophil count), uncomplicated neutropenic fever (low neutrophil count with a fever) and severe sepsis and shock (low neutrophil count, life threatening sepsis, with or without a fever). Neutropenic fever can quickly progress to sepsis and shock. It is these stages that represent a medical emergency that requires immediate treatment with intravenous broad spectrum antibiotics (acting before an identified pathogen or full blood count result are known) (NICE, 2012, The UK Sepsis Trust, 2013, Dellinger et al., 2013). This is because septic shock, can cause extensive infiltration of fluid into the tissues and a reduced blood supply to major organs, including the kidneys, liver, lungs and brain and consequently can cause death (The UK Sepsis Trust, 2013, Dellinger et al., 2013).

Importantly, NICE (2012) point to confusion regarding definitions of febrile neutropenia and neutropenic sepsis, resulting in such terms being used interchangeably by clinicians in practice. This is also the case with the literature cited and discussed within this chapter. Consequently, as adopted by NICE (2012), the term neutropenic sepsis is applied within this thesis to cover the range of illness from febrile neutropenia, to neutropenic sepsis that is also referred to as severe sepsis or septic shock.

Neutropenic sepsis is most likely to occur during initial chemotherapy treatments (e.g. cycle one or two) (Aapro et al., 2011). It is defined by the absolute neutrophil count and body temperature, although there is lack of consensus regarding the parameters for these indicators and they are based on low level evidence. NICE (2012) state that neutropenic sepsis should be diagnosed and treated in patients undergoing chemotherapy who have a neutrophil count of $0.5x10^9$ per litre or lower alongside either a temperature higher than 38^0C or clinical symptoms of sepsis, which may not include a fever. The Common Terminology Criteria for Adverse Events (CTCAE) (US Department of Health and Human Sciences, 2009) is also commonly used in clinical practice. Absolute neutrophil count and temperature parameters are not defined for grade one (mild) and grade two (moderate) neutropenia, which would not require medical treatment. Grade three and grade four neutropenia do fit with the NICE (2012) definition of neutropenic sepsis, although parameters of temperature and absolute neutrophil count differ. Grade 3 (severe) febrile neutropenia includes an ANC $<1.0x10^9$/L with a single temperature reading of $>38.3^0$C or a sustained temperature of $>38^o$C for more than one hour. The CTCAE suggests grade three neutropenia can rapidly progress to grade four (life threatening) neutropenia or neutropenic sepsis and septic shock (US Department of Health and Human Sciences, 2009).

Table 2.5. Stages of neutropenia (Based on: US Department of Health and Human Sciences, 2009, NICE, 2012, UK Sepsis Trust, 2013, Dellinger et al., 2013)

Normal	Neutropenia	Neutropenic Sepsis	
		Febrile neutropenia	Life threatening Severe Sepsis, Septic Shock
Absolute Neutrophil Count (Range 1.5-7.0 x10^{9})	Low Absolute Neutrophil Count without clinical symptoms (<1.5 x10^{9}) Often occurs between day 10-14 post chemotherapy (dependent on regimen)	Absolute Neutrophil Count 0.5x10^{9} per litre or lower Temperature higher than 38^{0}C (NICE 2012)	Neutropenic with or without a fever and symptoms of sepsis e.g. low blood pressure, confusion (CTCAE Grade four neutropenia)
		Absolute Neutrophil Count <1x10^{9} per litre with single temperature >38.3 or sustained temperature >38^{0}C for more than one hour (CTCAE Grade three neutropenia)	
		REQUIRE URGENT TREATMENT WITH INTRAVENOUS ANTIBIOTICS	

2.2.1.2. Neutropenic sepsis related incidence, mortality, morbidity and cost to the health service

The incidence of neutropenic sepsis within the UK is unknown due to differing definitions and the inability of healthcare clinical coding systems to adequately capture this (NICE, 2012). Data is available that suggests an increasing number of patients die from neutropenic sepsis each year within the UK (NICE, 2012) and studies have identified the incidence of death once this develops (Okera et al., 2011). In addition, evidence demonstrates sepsis is debilitating and expensive for the health service to treat (Kuderer et al., 2006; Vincent et al., 2006).

Data presented by NICE (2012) suggests deaths from neutropenic sepsis doubled within the UK between 2001 and 2010 to over 700 per year, which equates to around two per day. This increase reflects a rise in cancer incidence and associated chemotherapy usage within the UK, but is also likely to be an underestimate due to previously mentioned issues with clinical coding systems. Cancer has evolved into a chronic illness often controlled by multiple lines of treatment, including newer cancer drugs such as Taxanes and targeted therapies that have high risk indices for neutropenia. Another reason for the increase is the change to treatment approaches, informed by research showing a survival benefit with dose intensity in some chemotherapy regimens. Consequently, chemotherapy treatments are often not delayed to allow the absolute neutrophil count to recover which places patients at increased risk of developing neutropenic sepsis during subsequent treatments (Aapro et al., 2011).

Research suggests that mortality rates from neutropenic sepsis range from 2-21% of patients affected (Kuderer et al., 2006, Okera et al., 2011). A large American retrospective study of over 40,000 hospital admissions across 115 health centres, identified the overall hospital mortality rate from febrile neutropenia was 9.5% (range 0%-50%). Furthermore, mortality for patients with leukaemia (18%) was double that for patients treated for solid tumours (9%) (Kuderer et al., 2006). A more recent UK prospective study which included 61 patients over 71 hospital admissions for febrile neutropenia reported a mortality rate of 4.2% (Okera et al., 2011). Findings from these studies should though, be viewed with some caution. The UK study (Okera et al., 2011) may not be generalisable to the wider population, due to the small sample size and location within one cancer network within the UK. Furthermore, the mortality rate in the American study (Kuderer et al., 2006) may be an underestimate. The researchers relied on hospital coding to identify incidents of neutropenic sepsis, which they acknowledged may not have accurately captured all episodes. Okera et al (2011) overcame this problem by identifying cases of neutropenic sepsis through haematology laboratories and cross referencing these with patient hospital admission details.

Neutropenic sepsis is not only associated with mortality but has further harmful consequences. Morbidity or debilitation from sepsis often results in subsequent chemotherapy treatment delays and dose reductions, both of which have been shown to adversely affect prognosis, including in breast cancer (Chirivella et al., 2009).

Neutropenic sepsis also impacts on healthcare resources. Emergency assessment and treatment is required for all cases of neutropenic sepsis. Admission to hospital is required for some and intensive care management is needed for the most unwell patients (NICE, 2012). Limited data are available on healthcare financial burden associated with neutropenic sepsis. This does not include a breakdown of costs. A European Study published in 2006 suggests the cost of treating a patient who develops severe sepsis, including organ failure, is approximately £20,500 for intensive care treatment (Vincent et al., 2006). Furthermore, in the United States, the previously mentioned study of 41,779 patients admitted to hospital with neutropenic sepsis (Kuderer et al., 2006), identified the total cost of hospital admissions to exceed $1.06 billion, which equates to an average cost of £24,000 per episode.

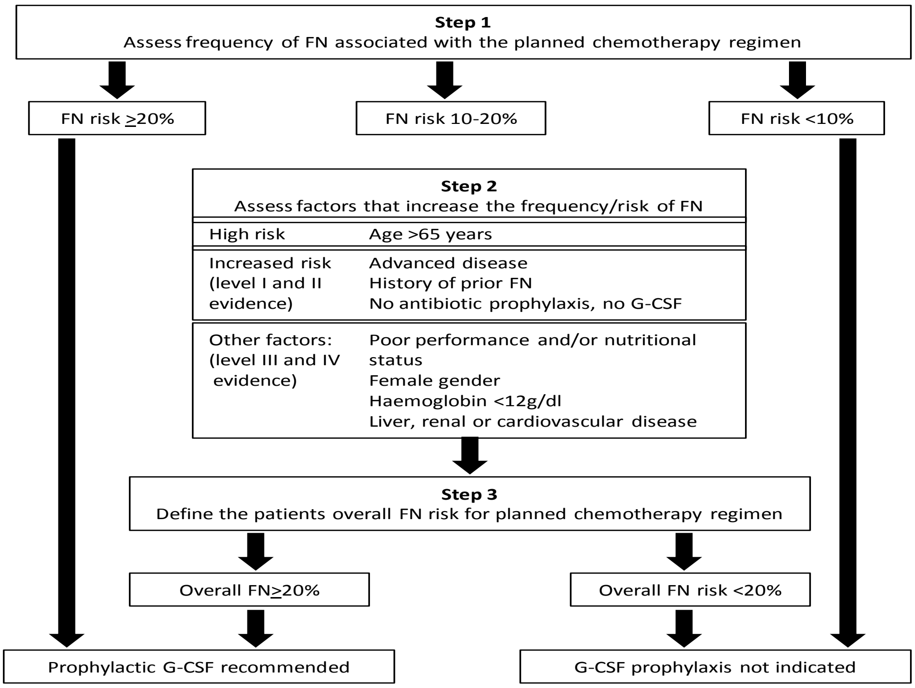
2.2.1.3 What predisposes patients to neutropenic sepsis and associated complications?

Evidence based guidelines produced by the EORTC (Aapro et al., 2006, Aapro et al., 2011) and ASCO (Smith et al., 2006) inform clinicians about chemotherapy drugs and patient risk factors, associated with a higher incidence of neutropenic sepsis. Guidelines produced by MASCC (Klastersky et al., 2000) suggest risk factors, that render patients at less risk of complications once this has developed. There is strong evidence, that chemotherapy drugs with a ≥20% risk of causing neutropenia and the presence of advanced cancer, put patients at greater risk of developing neutropenic sepsis (Aapro et al., 2006, Aapro et al., 2011). Furthermore, high level evidence suggests, age ≥65years as a risk factor for developing neutropenic sepsis (Smith et al., 2006, Aapro et al., 2006, Aapro et al., 2011) and complications from it (Klastersky et al., 2000). In addition, high level evidence suggests an increase in morbidity and mortality, in patients with co-morbidities, who develop, neutropenic sepsis following chemotherapy (Kuderer et al., 2006) and sepsis within the general population (Vincent et al., 2006).

ASCO (Smith et al., 2006) and the EORTC (Aapro et al., 2011, Aapro et al., 2006) have synthesised evidence to identify the risk factors that predispose patients to neutropenic sepsis. This process was carried out to inform guidelines for prescribing of prophylactic growth colony stimulating factors (G-CSF). This may be administered subcutaneously, as part of chemotherapy treatment to stimulate neutrophil production, thereby reducing the risk of developing neutropenic sepsis. High level evidence identified within these reviews, particularly in relation to chemotherapy drugs, age and advanced disease may also be used to inform clinicians and patients who might be at risk of developing neutropenic sepsis.

It is not clear if systematic processes were followed to retrieve and review the evidence that informed the ASCO guidelines, which may affect reliability and validity. The EORTC graded the evidence from level one to level five. Level one evidence related to meta-analysis of multiple well designed studies or high powered randomised controlled trials. Grade five evidence related to case reports and expert opinion. This assessment of quality of evidence was applied by the EORTC, to develop an algorithm to help clinicians to assess the risk of febrile neutropenia, for individual patients based on percentage risk of chemotherapy drugs administered and individual risk factors (Figure2.2). The majority of evidence for patient related risk factors was poor (level three-four). Level one evidence was identified for the following risk indices, which were included within the algorithm: being aged ≥65 years, having advanced disease and receiving no antibiotic prophylaxis. These risk factors were also identified, as important within the ASCO guidelines. Common chemotherapy regimens, considered by the EORTC to have a high (≥20%), or intermediate (≥10-20%) risk, of causing febrile neutropenia, were also identified and included within the algorithm. EORTC guidelines (figure 2.2) include patient risk factors for febrile neutropenia, that are supported by less robust evidence including: a previous neutropenic episode (EORTC grade two) and poor performance or nutritional status (EORTC grade three). Interestingly, receiving no G-CSF prophylaxis (EORTC grade two) is included as a risk factor for febrile neutropenia, alongside receiving no antibiotic prophylaxis (EORTC grade one), which may indicate a bias towards G-CSF. The rationale for including G-CSF prophylaxis is explained, through a concern not to cause antibiotic resistance (Aapro et al., 2011).

Figure 2.2. EORTC patient assessment algorithm (Aapro et al., 2011)
For permission see appendix 2



Not all patients who develop febrile neutropenia (CTCAE grade three) go on to develop neutropenic sepsis (CTCAE grade four). One study identifies predisposing factors for developing neutropenic sepsis that may also increase the risk of morbidity and mortality once this occurs. The MASCC risk index was developed through a multinational prospective study of 756 cancer patients with febrile neutropenia (Klastersky et al., 2000). The MASCC tool identifies patients at low risk of developing serious medical complications, once febrile neutropenia has developed. These patients may be managed more conservatively than patients with higher risk indices (Klastersky et al., 2000). Participants included adults >16 years, diagnosed with cancer, treated with chemotherapy and who subsequently developed neutropenia as defined by CTCAE (2009) criteria (ANC, $<0.5 \times 10^9$/L and fever, $>38^{O}$C). The median age of participants was 52 years. Three hundred and thirty one (44%) patients had a haematological malignancy, which reflects the population at risk of neutropenic sepsis. The researchers identified patient indicators in the presence of fever, which predicted a low risk of complications from neutropenia. Identified indicators were assigned integer weights, in order to calculate an overall risk index score which was subsequently validated. Indicators included, being aged < 60 years (OR 2.45; 95% CI 1.51-4.10) and having a solid tumour (OR 5.07 95% CI 1.97-12.95) as shown in figure 2.3. Validation demonstrated, that a score of $\geq$21 correctly identified patients at low risk of developing complications of neutropenic sepsis, with a positive predictive value of 91%, specificity of 68% (false positive) and sensitivity of 71% (true positive).

Although the MASCC tool is not used to predict patients at high risk of developing neutropenic sepsis, the risk indicators do identify factors that may make certain patients a riskier group once they have it, such as being aged $\geq$60 years, having chronic obstructive airways disease, having a haematology malignancy, or having a previous fungal infection within the duration of chemotherapy. Unsurprisingly, this suggests patients, who are less physically fit prior to developing neutropenic sepsis, are more likely to develop complications from it. This finding is reflected in a later American retrospective study of over 40,000 hospital admissions across 115 health centres, (Kuderer et al., 2006). This study identified that overall hospital mortality rates from febrile neutropenia was 9.5% and that high mortality risk was related to having major patient co-morbidities, such as heart disease, cerebrovascular disease, lung disease, diabetes mellitus, peripheral vascular disease and liver disease. Having no co-morbidities was associated with a 2.6% risk of mortality and one co-morbidity with a 10.3% risk. Patients who had more than one major co-morbidity had a 21.4% risk of dying from neutropenic sepsis.

Figure 2.3. **MASCC Risk index to identify low risk febrile neutropenia (Klastersky et al., 2000). For permission see appendix 2.**

Indicator	Comparison	Weight/ score	Odds ratio	95% Confidence interval
Burden of illness	Severe symptoms			
No or mild symptoms		5	8.21	4.15-16.38
Moderate symptoms		3	3.70	2.18-6.29
No hypotension	Hypotension	5	7.62	2.91-19.89
No chronic obstructive pulmonary disease	Chronic obstructive pulmonary disease	4	5.35	1.86-15.46
Solid tumour/lymphoma or no previous fungal infection	Haematological malignancy or previous fungal infection	4	5.07	1.97-12.95
No dehydration	Hydrated	3	3.81	1.89-7.73
Outpatients status at onset of fever	Inpatient status	3	3.51	2.02-6.04
Age <60 years	Age ≥60 years	2	2.45	1.51-4.01
MASCC (Multinational Association for Supportive Cancer Care)				

Taken together, the EORTC, ASCO and MASCC guidelines (table 2.6) may provide useful information showing which patients are at higher risk of developing neutropenic sepsis or are more at risk of complications once this develops. High level evidence suggests, important risk indices for neutropenic sepsis include, chemotherapy drugs that have a ≥20% risk of causing neutropenia and advanced cancer (Aapro et al., 2011, Aapro et al., 2006). In addition, high level evidence suggests, patients who are aged ≥65years are at greatest risk of developing neutropenic sepsis (Smith et al., 2006, Aapro et al., 2006, Aapro et al., 2011). Patients aged ≥ 60 years or who have co-morbidities, are further more likely to develop complications from neutropenic sepsis (Klastersky et al., 2000). Such information should influence communication with patients about the risks of neutropenic sepsis. Targeted information and monitoring towards those at greatest risk will be observed for within the current study.

Table 2.6. High level evidence for neutropenic sepsis risk factors

	Risk factor for developing neutropenic sepsis	**Increased risk of morbidity and mortality**
Chemotherapy regimen with 20% risk of neutropenia	EORTC (level one evidence) ASCO (high level evidence from clinical trials)	
Age	**Age ≥65 years** EORTC (level one evidence). ASCO (high level evidence)	MASCC ≥60 years (OR 2.45)
Haematological malignancy		MASCC (OR 5.07)
Advanced disease	EORTC (level one evidence) ASCO (high level evidence) from clinical trials)	
Co-morbidities		MASCC COPD (OR 5.35) Kuderer et al (2007) (% Mortality ± 95% CI) **0** 2.6. ± 0.2 **1** 10.3 ± 0.5 **2** 21.4 ± 1.1 **3** 38.6 ± 2.3 **4** 50.6 ± 5.3
No antibiotic prophylaxis	EORTC (level one evidence)	
References: MASCC (Klastersky et al., 2000); EORTC (Aapro et al., 2006; 2011); ASCO (Smith et al., 2006).		

2.2.2 Theme two: Symptoms of neutropenic sepsis that patients should report to clinicians

Clinicians want patients to identify changes in symptoms and functioning that possibly indicate neutropenic sepsis, and report these changes promptly in order to reduce morbidity and mortality. Seven low quality studies, that used convenience sampling, unsurprisingly suggest worsening neutropenia is associated with worsening physical and social functioning and symptom severity. Researchers have also developed scales suggesting symptom and function changes that indicate neutropenic sepsis. Importantly, these scales are designed to assist clinicians to identify neutropenic sepsis, rather than patients. Furthermore, there is a lack of evidence required to give definitive guidance regarding the degree of fever, or the associated symptoms indicating risk of neutropenic sepsis. Sources of infection are often not isolated and suggested symptoms of neutropenic sepsis are varied, and many - including diarrhoea and mucositis - are expected side effects of chemotherapy. These can occur in the absence of neutropenia. Evidence does exist for later signs and symptoms of septic shock, which include hypotension, high or low temperature, reduced urine output, confusion, unconsciousness and oedema. These symptoms are associated with delayed presentation and poor outcomes (Malik et al., 2001). There is consequently, a lack of evidence to support communication with patients and carers about early symptoms of neutropenic sepsis to report before these become more serious. Furthermore, patients may become confused by warnings of differing and multiple symptoms to look out for, which may or may not be important in determining the presence of neutropenic sepsis (NICE, 2012).

2.2.2.1 Effects of neutropenic sepsis on symptoms and functioning

Researchers from Memphis University attempted to understand the effects of different grades of chemotherapy-induced neutropenia (CTCAE, 2009) on symptoms and functioning. Two questionnaire based studies (Fortner et al., 2005a, Fortner et al., 2006) and a third qualitative interview study (Fortner et al., 2005b) attempted to understand the effects of worsening neutropenia. Findings across these studies suggest that reduced physical and social functioning is associated with worsening neutropenia. However, the studies are limited methodologically (e.g. use convenience samples, small sample sizes and exclude those prescribed G-CSF and chemotherapy regimens, with low risk indices for neutropenia). These limitations, and thereby the poor internal and external validity, reduce confidence in the findings. Consequently, changes in symptom and function identified within these studies cannot be confidently attributed solely to worsening neutropenia, or generalised to other patients who are at risk of developing neutropenic sepsis during cancer chemotherapy.

These longitudinal studies (Fortner et al., 2005a, Fortner et al., 2005b, Fortner et al., 2006) employed similar methodologies, including convenience sampling of patients with varied cancer diagnoses, undergoing a range of chemotherapy treatments likely to cause neutropenia. Grades of neutropenia were identified through blood tests, temperature readings and clinical assessments carried out at key points during the first 21 days of chemotherapy treatment. Grades were defined, according to the previously mentioned Common Terminology Criteria for Adverse Events (CTCAE) (US Department of Health and Human Sciences, 2009). Grade one (mild) and grade two (moderate) neutropenia, do not require medical treatment. Grade three (severe) febrile neutropenia and grade four (life threatening) neutropenia or neutropenic sepsis and septic shock (CTCAE 2009) require urgent treatment with intravenous antibiotics.

The initial longitudinal questionnaire single site study (Fortner et al., 2005a), found that patients (n=71) with grade four neutropenia were more likely to report increased bodily pain, less improvement in anxiety and reduced interest and participation in social activities, than those with grades 0-3 neutropenia. The second multicentre study (n=84) (Fortner et al., 2006), reported significantly worse scores for patients with grade 3-4 neutropenia, than those with grades 0-2 neutropenia, for physical symptom distress, overall valuation on life, depression and isolation. Results from both studies, should be viewed with caution, though as sampling strategies, including power calculations and response rates are not clearly described. Participant numbers are small, which means the studies are likely to be underpowered. This may be further compounded within the second multicentre study (Fortner et al., 2006), as the clustering design (shared characteristics of patients and clinical practice, within each of the nine included healthcare settings) would have required an increased sample size, to be adequately powered. The precision of effect sizes (size of the difference in symptom severity between grades of neutropenia) is difficult to interpret, due to the authors omitting confidence intervals. Type two errors are likely, which mean non-significant findings may actually be significant. Regardless, the effect sizes were small for most statistically significant findings across both studies e.g. bodily pain (0.37) (Fortner et al., 2005a), so may not be clinically meaningful. A potentially important (though unsurprising) finding was the large effect sizes identified within the second study (Fortner et al., 2006) for reduced physical and social functioning. Patients who developed grades 3-4, compared to those with grades 0-2 neutropenia had significantly worse physical and social functioning scores (Physical functioning grade 0-2 adjusted mean 1.59 (standard error 6.91) grade 3-4 adjusted mean -8.70 (7.42); Social functioning grade 0-2 adjusted mean 10.80(8.20) grade 3-4 adjusted mean -1.12(8.64).

The third study (Fortner et al., 2005b) was a qualitative study comprising 100 interviews with 34 patients, who developed grade four neutropenia during their first cycle of chemotherapy. Interviews were provisionally scheduled for days 7, 10, 14 and 21 following chemotherapy but were commenced at the point patients developed grade four neutropenia. Consequently, only data collected from patients who developed grade four neutropenia were included in the final analysis. Fatigue was identified as the most frequent and overwhelming symptom of chemotherapy (n=31, 91%). Over half the patients interviewed (n=19, 56%) noted their normal daily routine was interrupted as a result of chemotherapy treatment. They reported a loss of usual roles, as they were unable to take part in normal physical and social activities that made life pleasurable. Over a quarter of patients told interviewers they dreaded starting the next chemotherapy treatment and felt low as a consequence of chemotherapy side effects. This study also identified physical symptoms in patients with grade four neutropenia including: muscle aches, feeling achy or swollen joints (n=13, 38%) pain (n=10, 29%) and cough, sore throat, mucous in throat or difficulty swallowing (n=8, 24%). This study may be criticised because interviews only took 20 minutes, which is unlikely to have been long enough to capture an in-depth picture of significant issues for patients. Furthermore, it is not clear from the report, what training was provided for the psychology students who conducted the interviews, the questions asked, whether these were open or closed for example or how consistency between interviews was ensured. The researchers also did not include interview data from patients with different grades of neutropenia, so it is not possible to attribute identified changes in symptoms and functioning solely to grade four neutropenia.

Although the University of Memphis series of studies suggest an unsurprising association, between worsening symptoms and functioning and worsening neutropenia, they do not provide evidence of specific symptoms associated with grades three and four neutropenia that patients need to recognise and report urgently to clinicians. In addition to limitations posed by convenience sampling, most participants were white, highly educated women, usually with a diagnosis of lung or breast cancer. Patients admitted to hospital with neutropenia, who would be the most unwell, were further under represented. The authors did not explore symptom clustering in relation to neutropenia. They failed to discuss possible reasons for psychological symptoms associated with declining ANC, which may in part relate to neutropenic imposed isolation and treatment delays, rather than an intrinsic aspect of neutropenia.

2.2.2.2 Can knowledge about presenting symptoms of neutropenic sepsis assist in early identification?

Researchers have identified symptoms in patients who present to hospital with neutropenic sepsis. They have also developed scales based upon symptom clusters that aim to assist clinicians to diagnose neutropenic sepsis. This evidence is unlikely to assist patients to identify early symptoms of neutropenic sepsis. This is because studies lack internal and external validity. Neutropenic symptom scales have been developed for clinician, rather than patient use and interpretation, through the use of technical terms, definitions and measures. Furthermore, there is lack of consensus regarding the body temperature that indicates a risk of neutropenic sepsis. Other proposed associated symptoms cannot be distinguished from the expected side effects of chemotherapy for everyone. High quality evidence does identify later and more serious symptoms of septic shock.

Only one small UK study (Higgins and Hill, 2012) presents body temperature in patients diagnosed with neutropenic sepsis. This study reports on an audit of a neutropenic sepsis clinical pathway across a cancer network, using a review of 88 patient admissions to hospitals over a period of six months. Presenting temperatures were found to range from below 36^{o}C to 40^{o}C, with the majority of patients having a temperature between 37.5^{o}C and 40^{o}C. This suggests the focus of a temperature of around 38^{o}C, as cited within definitions of neutropenic sepsis (US Department of Health and Human Sciences, 2009, NICE, 2012), as an indicator to patients of neutropenic sepsis may not be reliable.

Two further studies report the symptoms of neutropenic sepsis that patients present to hospital with (Nirenberg et al., 2004, Okera et al., 2011). Researchers within the UK, studied 71 patient admissions to hospitals with neutropenic sepsis, involving 64 patients (Okera et al., 2011). The researchers found that patients presented with the following key infection related symptoms: respiratory (49%); gastrointestinal (46%); and mucositis (18%). More female (59%) than male (41%) patients with a range of cancer diagnosis were reviewed. The median age was 60 years (20-78 years). Four deaths occurred, three of which were related to neutropenic sepsis. Demographics, such as ethnicity and socioeconomic status are not stated within the paper, so results may not be generalisable to different socio-cultural communities.

A second prospective descriptive study of a small number of patients (n=19), who presented to American emergency departments with febrile neutropenia following chemotherapy, identified seven (37%) who experienced mucositis, and 11 (58%) who had a central venous access device (CVAD) in situ, which may have represented a source of infection. Participants included equal numbers of male and female and Caucasian and non Caucasian patients (Nirenberg et al., 2004).

Difficulties with capturing the data for all episodes of neutropenic sepsis, including inconsistencies in definitions, are likely to have affected internal and external validity of findings, across these studies. Okera et al., (2011) were unable to identify patients admitted with neutropenic sepsis to hospitals, outside the cancer network. Nirenberg et al., (2004) could not capture episodes, where patients presented directly to doctors, who took their own night calls. Higgins and Hill, (2012) acknowledge problems with data collection. Further, it was unclear how patients were identified for inclusion in their study.

Suggested symptoms of neutropenic sepsis are further detailed within the Patient Care Monitor Neutropenia Index (PCM-N) (table 2.7). This was developed by the Memphis University researchers, on the basis of previously mentioned studies, in an attempt to measure differences between grades of neutropenia. The PCM-N quality of life tool was designed to measure 13 symptom and function changes associated with neutropenia. The PCM-N was developed from items within a database of symptoms present in patients, who developed neutropenia (approximately 10,000 observations), a literature review and expert opinion. Thirteen items for the PCM-N scale were generated and patients scored items on a tablet computer, out of 10, with a score of 0 meaning no problem and a score of 10 being the worst case scenario. Scores range from 0-130, with higher scores being correlated with increased symptom and functioning burden associated with neutropenic sepsis (Fortner and Houts, 2006, Olsen et al., 2011).

Table 2.7. Items on the Patient Cancer Monitor 1.0 Revised Neutropenia Index (Olsen et al., 2011). For permission see appendix 2

Item	Item-total correlation	Alpha if Item deleted	Factor Loading
Fatigue, tiredness, or weakness	0.61	0.81	0.663
Trouble with bowel movements (e.g. diarrhoea, constipation)	0.49	0.83	0.503
Sore throat or trouble swallowing	0.53	0.82	0.645
Reduced sexual enjoyment, interest or performance	0.38	0.84	0.424
Trouble sleeping	0.53	0.82	0.576
Nausea or vomiting	0.54	0.82	0.621
Numbness or tingling	0.47	0.83	0.479
Dry mouth	0.61	0.82	0.695
Loss of interest in people he or she used to want to be around	0.47	0.83	0.482
Fever or chills	0.54	0.82	0.653
Swollen glands	0.4	0.83	0.493
Headache	0.46	0.83	0.705
Mouth sores	0.39	0.83	0.529

2.2.2.3 Validation of the PCM-N

Two studies report use of the PCM-N. In the first study, Fortner and Houts (2006) extrapolated patient (n=51) self-report symptom data from the PCM-N index. This was correlated with absolute neutrophil counts (ANC data). Key results indicated that PCM-N identified symptom burden scores, were higher in patients with grade 3-4 neutropenia (n=24), than those with grades 0-2 neutropenia (n=27). Results should be viewed with caution because these are based on a small sample. Only 51 out of 741 (7%) consented eligible patients could be included in the study, due to incomplete data in the remaining cases. This low response rate is not explained by the authors, but may indicate lack of acceptability of the scale to patients, and/or difficulty in capturing data at pre-determined time frames. The small sample size means, that the study may have been underpowered, to detect other significant findings. Furthermore, details were not provided about who collated the data. The quality control may have been compromised, if multiple coders were involved. The tool does not include 'anchors' or descriptions of scores for each level, on the scale to help ensure reliability between different raters.

Within a second study, Olsen et al., (2011) gathered data from four samples, one of which was the sample from the study described above (thereby the same methodological limitations were applied). The researchers pooled the samples (n=424) to test the psychometric properties of the PCM-N. As with previous Memphis studies, this demonstrated an association between worsening neutropenia and worsening symptoms. The PCM-N demonstrated discriminant validity in terms of being able to distinguish between patients with grades 3-4 neutropenia and those with grades 0-2 neutropenia ($p<0.05$). The researchers also tested the internal consistency of the scale in each of the four samples. They found strong internal consistency (0.81-0.91). This suggests it is an internally valid model.

One way ANOVA was applied to sample four (n=90), to compare PCM-N scores for three differently graded neutropenia status groups (febrile neutropenia, non febrile neutropenia and no neutropenia). The result showed, that there were differences between the groups ($F [2, 87] =44.67$, $P<0.001$). Tukey post hoc comparisons (conducted to identify where the differences lay) demonstrated poorer scores in both neutropenia groups than the non neutropenic group. Patients with febrile neutropenia had poorer scores than non febrile neutropenic patients. In order to determine the accuracy of the PCM-N, the authors also conducted a Receiver Operator Characteristic (ROC) analysis, in combination with Youden's index scores with sample four, to determine the most psychometrically robust threshold score. Results suggest that a score of 20 (out of 130) or higher is sensitive to 81% of patients with neutropenia (febrile neutropenia or non febrile neutropenia) and 78% of patients who did not have neutropenia (sensitivity, true positives 81% and specificity, false positives 22%). Because the study was designed to test the PCM-N psychometrics, no details of frequency of symptoms experienced or clusters of symptoms, at different grades are reported.

In summary study findings indicate that the PCM-N tool could have good sensitivity/specificity for identifying patients requiring treatment for neutropenic sepsis. In addition, the research that informs the PCM-N suggests neutropenic sepsis presents, as a complex profile of symptoms that all contribute to one overriding factor (neutropenic sepsis). It may be the severity of symptom clusters that are important indicators of it, rather than individual symptoms.

The FACT-N (Wagner et al., 2008) is another patient self-report tool, designed to measure patient symptoms related to neutropenia. The 19 items for the FACT-N were generated through patient and clinician interviews and subsequent identification of items perceived to be important from an existing bank of cancer symptoms. Although a study (Wagner et al., 2008) suggested the FACT-N may be sensitive to the presence of neutropenia, the researchers were unable to demonstrate the ability of it to distinguish between grades of neutropenia. This is likely to be important to patient symptom reporting because patients need to understand, which symptoms indicate neutropenic sepsis. The PCM-N appears to be a more clinically applicable and robust tool than the FACT-N because this is able to distinguish between grades of neutropenia. The PCM-N is though, only able to identify general changes associated with grade three and four neutropenia, rather than specific symptoms. It does not help identify early symptoms which should be highlighted to patients. Furthermore, it was designed for clinicians to interpret, so the acceptability of it as a tool to assist patients in recognising, when they need to contact clinicians remains unknown.

2.2.2.4 Signs and symptoms of life threatening neutropenic sepsis / septic shock

Neutropenic sepsis is life threatening once this progresses to CTCAE grade four neutropenia, also defined as severe sepsis and septic shock (US Department of Health and Human Sciences, 2009; NICE, 2012; Dellinger et al., 2012, UK Sepsis Trust, 2013). In terms of worsening prognosis NICE (2012) found low level evidence of symptoms related to patients with fever and neutropenia that predict poor outcomes, including death, need for critical care, having unresolved fever and bacteraemia. Specific symptoms identified with poorer prognosis included: mucositis, feeling generally unwell (which fits MASCC's identification of symptom burden as a prognostic factor for complications), temperature over 39^{o}C, clinical signs of infection, chills and confusion. NICE (2012) found no evidence for flu-like symptoms (e.g. aching and feeling hot and cold), rigor, diarrhoea, vomiting or carer worry, as predicting poorer outcomes from neutropenic sepsis. A further prospective study conducted over five years in Pakistan (Malik et al., 2001), identified symptoms associated with neutropenia induced septic shock. The researchers reviewed 576 episodes, where adult patients over 16 years presented to hospital with neutropenic sepsis. The researchers identified 22 (3.8%) of the 576 patient episodes related to septic shock. They compared outcomes for this group with the remaining patients with neutropenic fever, who did not develop septic shock. Significant symptoms of septic shock were reported as diarrhoea, altered mental state, bleeding, and dyspnoea. The effect sizes and their precision (confidence intervals) are not presented in the paper (only the P value is provided). The comparison of 22 (3.8%) with 544 (96.2%) neutropenic sepsis admissions is likely to be underpowered to detect differences, so other clinically meaningful symptoms between the two groups may not have been statistically significant.

2.2.2.5 Relevance of sepsis within the general population

There appears to be a disconnect in the literature between studies that explore symptoms of neutropenic sepsis and studies that explore general clinical knowledge about the condition of sepsis, which can arise in cancer and non cancer populations. Patient information about symptoms associated with worsening sepsis, has been developed by the UK Sepsis Trust (2012) (table 2.8). Many of these symptoms have been reported within studies examining the presenting symptoms of neutropenic sepsis, reported in this chapter. High quality quantitative and qualitative studies are required, to accurately and simply describe typical symptoms of neutropenic sepsis to help patients identify and promptly report it to clinicians. It may, for example be important to identify if mucositis or difficulty eating, are early indicators of neutropenic sepsis because these may be obvious early symptoms for patients to report. It may also be the severity of symptom clusters that are important.

Table 2.8. Symptoms of sepsis (The UK Sepsis Trust, 2012)

Early symptoms	As worsens	As progresses
Cold and shivery Hot and flushed High temperature Aching muscles Tired Nausea and vomiting Not feeling like eating Confusion / slurred speech	Low blood pressure Fast pulse rate Shortness of breath Skin; cold, pale, mottled, hot or flushed	Lower blood pressure Reduced urine output Worsening shortness of breath Darkening and blistering skin Confusion, unconsciousness Oedema

2.2.3 Theme three: Knowledge about delayed patient presentation to hospital with neutropenic sepsis.

Neutropenic sepsis is a dangerous side effect of chemotherapy. CTCAE grade four neutropenic sepsis (severe sepsis or septic shock), which manifests through organ failure and tissue hypoperfusion (Dellinger et al., 2013) is associated with late identification and treatment of neutropenic sepsis and increased risk of death (National Confidential Enquiry into Patient Outcome and Death, 2008). A study carried out in Pakistan (Malik et al., 2001) reported that 82% of patients who developed septic shock from neutropenic sepsis died, mostly within 72 hours of hospital admission. Within the UK, the mortality rate for those developing sepsis within the general population is 30%. For septic shock this rises to 50% (Bernard et al., 2001). Furthermore, each hour of delayed treatment with intravenous antibiotics for septic shock is associated with an 8% increase in mortality (Kumar et al., 2006). The literature regarding safe management of neutropenic sepsis is focused on early intervention with intravenous antibiotics, to be given within one hour of patients presenting to hospital, if neutropenic sepsis is suspected. Indications for administration of intravenous antibiotics before the neutrophil count is known include recent treatment with chemotherapy, a temperature over 38^{o}C and other clinical symptoms of sepsis (NICE, 2012).

There is also an under researched clinical concern that late reporting of neutropenic sepsis arises, despite clinicians thinking they convey risks of this, and actions to take if symptoms of it develop (including providing patients with 24-hour on-call telephone numbers) (Nirenberg et al., 2004). At the outset of this study no research could be identified that specifically explored why patients delay presenting to hospital when they develop neutropenic sepsis. Some studies provide data that suggest such delays may range between 24-hours and seven days (Malik et al., 2001, Nirenberg et al., 2004, National Confidential Enquiry into Patient Outcome and Death, 2008, McKenzie et al., 2011, Royal College of Physicians, 2012, Higgins and Hill, 2012). A retrospective UK study published by the National Confidential Enquiry into Patient Outcomes and Death (NCEPOD 2008) investigated deaths following chemotherapy administration and identified areas of poor practice in relation to neutropenic sepsis. Data collected within this study included an organisational questionnaire, which was completed by each hospital, who declared themselves as systemic anti-cancer treatment (SACT) providers. This identified staffing numbers, facilities and local protocols relating to neutropenic sepsis. Data were also collected on patients who were treated with SACT over a two month period and who had died within 30 days of treatment. Patient case notes were reviewed and two questionnaires were completed for each identified patient. The first questionnaire related to the treatment plan and chemotherapy administration and was completed by the treating consultant. The second questionnaire related to follow up, toxicity and death. It was completed by the consultant responsible for the care of patients who died as inpatients or by the treating consultant where patients died in the community.

Evidence was reviewed by a multidisciplinary expert advisory group which included haemato-oncologists, medical and clinical oncologists, a palliative care doctor, pharmacists and chemotherapy nurses. Quantitative data were analysed descriptively, using Microsoft Access and Excel. Qualitative data, from questionnaires were coded and reviewed by NCEPOD staff to identify recurring themes. Of 546 cases reviewed during the NCEPOD enquiry, 83 patients developed neutropenic sepsis and all were admitted to hospital. The report identified that some patients delayed presentation to emergency departments with severe, classified as CTCAE grade three or four, symptoms of neutropenic sepsis by at least 24-hours. Although data on the number of patients who delayed is not presented, this is a valuable report which provides the first indication in the UK that some patients delay presenting to hospital with neutropenic sepsis.

Further studies also provide data, which demonstrates that some patients present late to hospital with signs and symptoms of neutropenic sepsis. A prospective descriptive American study (Nirenberg et al., 2004) found that 23 patients admitted to the emergency department and diagnosed with neutropenic sepsis had been aware of a fever for a mean of 21-hours (range 1-72) before seeking help from clinicians. Delayed patient presentation with signs and symptoms of neutropenic sepsis, were also noted by Higgins and Hill (2012) during the previously mentioned retrospective audit of a UK cancer network neutropenic sepsis clinical pathway. A case note review (n=88) revealed 30% of patients admitted to hospital with neutropenic sepsis, waited for over 24-hours before presenting to hospital. A subsequent patient survey was sent, although this did not ask about delayed presentation/reporting of symptoms.

A further patient survey (n=262) about acute oncology care (Royal College of Physicians, 2012), identified patients who delayed presenting to hospital with a range of conditions for two days or more. This included patients who were subsequently diagnosed with neutropenic sepsis, although the number of patients this related to is not provided within the report. Interestingly, patient delays for a variety of cancer related conditions occurred despite 90% of respondents indicating they had been informed about chemotherapy symptoms to report (although their knowledge was not tested), and were provided with helpline numbers. A final Australian retrospective study (McKenzie et al., 2011) explored the nature and occurrence of unplanned admissions to hospital over one year amongst patients treated with chemotherapy for a solid tumour within the previous six months. Results suggested that 316 patients made 469 unplanned visits to the cancer centre or emergency department. Of these 233 patients (73.7%) accounted for 363 admissions to hospital. 23.4% of admissions were related to fever or febrile neutropenia. Of all patients presenting to hospital, the mean age was 58.9 years, with equal numbers of male and female participants presenting. The most common malignancies were breast, lung and colorectal. The authors found that patients with a range of symptoms, frequently delayed presenting between two and seven days but as with the previous study, the finding was not specific to neutropenic sepsis.

In terms of riskier groups, patients with co-morbidities or advanced cancer were suggested in one study to wait longer than other patients to present to hospital with neutropenic sepsis (Nirenberg et al., 2004). A further study (Malik et al., 2001) identified cancer patients who presented to hospital with septic shock (CTCAE grade four neutropenia) as having advanced disease and being significantly older than patients with febrile neutropenia (CTCAE grade three neutropenia). Together this research (Malik et al., 2001, Nirenberg et al., 2004) suggests that being older and having reduced functionality may be risk factors for patients delaying presenting to hospital with neutropenic sepsis.

The research carried out in Pakistan (Malik et al., 2001) also identified that patients in septic shock tended to present to an emergency department (Malik et al., 2001). This appears similar in the UK. The NCEPOD (2008) study that reviewed the care of patients who died within 30 days of chemotherapy (including deaths from neutropenic sepsis) found the majority of patients admitted to hospital initially presented to A&E departments. Within the study conducted by Malik et al, (2001) the mean duration of fever before admission (standard deviation in brackets) was reported to be 9.2(17.6) for the septic shock and 3.1(5.2) for the non septic shock group (Malik et al., 2001). This suggests there may be an association between delayed presentation to hospital and septic shock. It is not clear from the research paper, however, if this data refers to hours or days and attempts to clarify this with the researchers have not been successful. As previously mentioned, this study was likely to be underpowered to detect smaller effect sizes that may also be clinically meaningful.

These findings concur with level one evidence cited earlier within this chapter that patients who are older, or have advanced disease are at higher risk of developing neutropenic sepsis (Smith et al., 2006, Aapro et al., 2011). Furthermore, increased morbidity and mortality in patients who develop neutropenic sepsis following chemotherapy is related to age $\geq$ 60 years (Klastersky et al., 2000) and the presence of co-morbidities (Klastersky et al., 2000, Kuderer et al., 2006). Within the general population, patients aged $\geq$ 65 years also experience worse outcomes from sepsis, than younger patients (The UK Sepsis Trust, 2013).

Across these studies, most patients presented with neutropenic sepsis within 10-14 days of chemotherapy either direct to oncology, haematology or emergency departments. Prior to conducting the study presented in this thesis, reasons for delays had not been systematically studied. Assumptions within studies include information about neutropenic sepsis solely being provided to patients at the start of chemotherapy (NCEPOD, 2008), patients not understanding the urgency for reporting neutropenic sepsis symptoms, and/or poor explanations of neutropenic sepsis by clinicians (NCEPOD, 2008, Higgins and Hill, 2012). Further assumptions for patient delays, include: (1) that they were too unwell to go to hospital (Malik et al., 2001, Royal College of Physicians, 2012); and (2) not wanting to bother clinicians or to go to hospital when they developed neutropenic sepsis (Nirenberg et al., 2004, McKenzie et al., 2011). Provider delay, was also identified as an issue by The Royal College of Physicians (2012) who found patients sometimes made contact with clinicians, who themselves failed to recognise the importance of symptoms of neutropenic sepsis at an early stage.

2.2.4 Theme four: Education of patients about neutropenic sepsis.

This chapter has identified that some patients may be at greater risk of developing neutropenic sepsis depending on treatment and patient factors. Particular symptom and functional changes may or may not indicate the presence of neutropenic sepsis. Patients can present late with such symptoms, which increases the risk of septic shock and death. The reasons for patient delays remain unknown. Neutropenic sepsis further typically occurs when patients are at home. Consequently, patients and their carers are responsible for recognising symptoms of this in order to promptly report these to the hospital. The National Chemotherapy Advisory Group (NCAG, 2009) responded to concerns highlighted within the NCEPOD (2008) report, that greater attention should be paid to education, to prepare patients to recognise and report symptoms of neutropenic sepsis by advising:

> *All patients should be given both verbal and written information about their treatment, likely side effects and whom they should contact if problems arise (either within or outside normal working hours). All patients should have access to 24-hour telephone advice with active management of access to appropriate emergency care.* (NCAG, 2009; p6)

Consequently, patients in the UK are required to have access to 24-hour on-call services, if they are at risk of developing neutropenic sepsis as a result of oncology treatment, according to standards set out through a peer review process (NICE, 2012, National Cancer Peer Review - National Cancer Action Team (NCAT), 2011). Further, newer acute oncology standards requires emergency cancer services to be provided for patients, who become unwell due to cancer or cancer treatments, including those who develop neutropenic sepsis (National Cancer Peer Review - National Cancer Action Team (NCAT), 2013). Patients are typically given information about how to recognise and report symptoms of neutropenic sepsis when a doctor takes written consent for chemotherapy and during a chemotherapy nurse led pre-treatment consultation. Importantly, the rationale for timing of information delivery about neutropenic sepsis is not evidence based. Twenty-four hour on-call telephone numbers are provided for patients, further information about neutropenic sepsis may be given at subsequent visits and obtained by patients and carers via other sources, such as the internet (Higgins, 2008, NCAG, 2009). Patients who develop symptoms of neutropenic sepsis, may subsequently present to A&E departments or direct to acute oncology services.

Clinicians consider supporting patients, to recognise and report neutropenic sepsis to be an important part of their role (Nirenberg et al., 2006b, Nirenberg et al., 2010). The American Oncology Nursing Society explored nursing knowledge and practice in relation to the management of patients with neutropenic sepsis within two studies (Nirenberg et al., 2006b, Nirenberg et al., 2010). The first study (Nirenberg et al., 2006b) was based on a review of available literature and neutropenic sepsis management guidelines from hospitals across America, which were discussed at an oncology nursing symposium. Within the subsequent study, Nirenberg et al., (2010) aimed to describe oncology nurses use of National Comprehensive Cancer Network (NCCN) clinical practice guidelines for chemotherapy induced neutropenia, and to test their knowledge of evidence based standards. A cross sectional, purposive sample (n=309) of members of the oncology nursing society (N=3,834), completed a web based questionnaire. Both studies indicate that oncology nurses viewed themselves as playing a role in educating patients about neutropenic sepsis and Nirenberg et al., (2010) found 84% of surveyed oncology nurses believed they had a professional obligation to undertake risk assessments and to deliver patient education to help patients identify and report symptoms of neutropenic sepsis.

In terms of perceived nursing confidence and competence most respondents within the second study (Nirenberg et al., 2010) indicated they felt able to identify patients at risk of developing neutropenic sepsis (97%) and that they provided instructions for patients about post chemotherapy home care (98%). Knowledge scores were generally high. Experienced nurses with advanced qualifications had significantly higher perceived confidence and competence scores (certification, None 13.5 SD 2.1; General 14.9 SD 1.5; Advanced 15.7. SD 0.8) and were more likely to answer questions correctly. Sampling bias is though, evident, which means the population is under represented: only 8% of the population sample responded, who were more highly educated and experienced than average oncology nursing society members.

Importantly, although nurses may feel confident in preparing patients for the possibility of neutropenic sepsis, NICE - within evidence based guidance (NICE 2012) - point to a lack of evidence for interventions to assist patients with this process. This includes, as identified earlier in this chapter, poor evidence for symptoms of neutropenic sepsis. Consequently, it is unsurprising that Nirenberg et al (2006b) found a lack of nursing knowledge to guide the education of patients about neutropenic sepsis. Nirenberg (2006b) identified vast inconsistencies across neutropenic sepsis patient management guidelines, including in relation to the symptoms of neutropenic sepsis and the severity of these that patients should seek support for. A key and important inconsistency, concerns the level of fever that patients should report, which reflects a lack of scientific knowledge regarding body temperature indicative of neutropenic sepsis (Nirenberg et al., 2006b, NICE, 2012). Poor knowledge to identify symptoms of neutropenic sepsis is also evident within chemotherapy patient education literature. An example is information provided for patients and carers on the UK's Macmillan Cancer Support website at www.macmillan.org.uk (Macmillan Cancer Support), who advise patients to contact a clinician simply if they develop a temperature above 38^{o}C or if they suddenly feel unwell, even with a normal temperature. Importantly, Nirenberg et al (2006b) also identified that only 39% of nurse respondents indicated they knew that the risks of patients developing neutropenic sepsis are higher during the first chemotherapy cycle; which the authors state is knowledge that may be of use when educating patients and families at the start of treatment.

In addition to poor evidence on which to base neutropenic sepsis symptom advice, interventions commonly used to support patients undergoing chemotherapy (such as patient information, DVDs and newer telephone based chemotherapy symptom logging systems) have not been evaluated in relation to promoting early patient presentation with symptoms of neutropenic sepsis. Suggested verbal or written approaches to assist patients to present early with symptoms of neutropenic sepsis are also not research based. These include explaining the risks and consequences of neutropenic sepsis, the reason for early treatment with antibiotics and who to call if symptoms of neutropenic sepsis occur (Nirenberg et al., 2004, Nirenberg et al., 2006a, NCAG, 2009). Some authors argue that proactive monitoring and support should be provided for patients at home, in order to help them manage symptoms of chemotherapy, (Nirenberg et al., 2010, NCAG, 2009). As with other interventions the impact of this on the reporting of neutropenic sepsis remains unknown.

It can be inferred from NCAG guidance (2009), that provision of 24-hour on-call services for patients undergoing chemotherapy will promote early patient presentation and treatment for neutropenic sepsis. Only one small UK questionnaire study (Higgins, 2008) evaluated an intervention based upon this type of service. This study explored patient experience with a chemotherapy alert card, linked to a specialist 24-hour on call service. One side of the alert card provided details of symptoms for patients to report urgently and the other side of the card provided clinical management advice for clinicians. The questionnaire contained nine multiple choice questions and three open questions. This focused on what patients found most helpful and unhelpful about the alert card, with space for other comments. Fifty seven patients returned the questionnaires from three hospitals within one cancer network. Most respondents (89%) said they had been provided with the alert card and 82% said they carried it with them at all times. Patients found it reassuring to have the card, which made them feel safe. The study sampling frame is not described and therefore the response rate is unclear. Further, the focus is on acceptability of the alert card to patients and not on their use of it. Consequently, the impact of the alert card and availability of 24-hour helplines on promoting early presentation with neutropenic sepsis remains unknown.

2.3 Chapter conclusion

In conclusion, limited evidence suggests patients sometimes delay contacting clinicians, when they develop neutropenic sepsis and the extent and reasons for this behaviour are unknown. Clinicians are likely to struggle to communicate clearly with patients about the symptoms of neutropenic sepsis, because there is no consensus on the early indicators of it. Consequently and importantly, patients are likely to be confused about which symptoms they should expect following chemotherapy and those that may indicate neutropenic sepsis and should be reported to clinicians urgently. The lack of evidence to help clinicians convey to patients, how they are likely to feel during a neutropenic sepsis episode, led NICE (2012) to recommend a prospective study is carried out, to identify symptoms that predict neutropenic sepsis in patients in the community. NICE (2012) further recommend that qualitative studies are conducted, to explore how effective information exchange between patients and clinicians about neutropenic sepsis may be achieved. The study outlined within this thesis aims to go beyond NICE guidance to understand why patients delay reporting symptoms of neutropenic sepsis to clinicians and to identify potential factors that may encourage earlier presentation. These may then be explored through future intervention studies. Within this study, close attention will be paid to how clinicians, patients and carers communicate about neutropenic sepsis and how clinicians draw upon available - albeit weak - knowledge about neutropenic sepsis symptoms, and on stronger evidence regarding risk factors to educate and support patients.

Chapter summary:

Previous research has not studied how risks of neutropenic sepsis are communicated or why patients delay presenting to hospital when this occurs. A scoping review of the literature synthesised knowledge about neutropenic sepsis, the risks of this to patients, reasons for delayed presentation and good practice in communicating risk. The evidence was mapped within four themes, thought to be important to the research outlined within this thesis. Judgments about the strength of the evidence were made through application of the Critical Appraisal Skills Program (CASP) tool for reviewing qualitative research and the Quantitative Critical Review Form.

Theme one identified neutropenic sepsis as a life threatening immunosuppressive complication of chemotherapy, which accounts for a significant number of high cost hospital admissions and at least two deaths each day within the UK (NICE, 2012). Definitions of neutropenic sepsis differ, although distinctions are always made between early febrile neutropenia and later sepsis. High level evidence suggests risk factors for developing neutropenic sepsis. These include regimens with $\geq$20% risk of causing neutropenia, age $\geq$ 65 years and advanced disease (Smith et al., 2006, Aapro et al., 2011). Furthermore age $\geq$ 60 years or the presence of co-morbidities is associated with an increased risk of complications once neutropenic sepsis develops (Klastersky et al., 2000).

Studies reviewed within theme two do not identify symptoms of neutropenic sepsis that patients should look out for. Evidence unsurprisingly, suggests declining physical and social functioning are associated with worsening neutropenia (Fortner et al., 2006). More specific symptoms, that patients should recognise and report to clinicians, cannot be defined or distinguished from expected chemotherapy side effects (Olsen et al., 2011, Okera et al., 2011). These require further exploration through large high quality prospective cohort studies. Stronger evidence exists regarding later symptoms of CTCAE grade four neutropenic sepsis (severe sepsis / septic shock), that include shortness of breath, oedema and confusion, but these are also associated with poorer clinical outcomes (Malik et al., 2001, The UK Sepsis Trust, 2012, Dellinger et al., 2013).

Theme three identified studies that suggest patients may delay presenting to hospital with symptoms of neutropenic sepsis by two days or more (NCEPOD, 2008; NCAG, 2009; Nirenberg et al., 2004; McKenzie et al., 2011; Royal College of Physicians, 2012). The reasons for such delays remain unknown. Weak evidence suggests, patients with advanced disease (Nirenberg et al., 2004, Malik et al., 2011), or with co-morbidities (Nirenberg et al., 2004) and those aged ≥ 65 years (Malik et al., 2001), may delay reporting symptoms of neutropenic sepsis for longer and thus become more unwell than fitter or younger patients. This is a concern, as those who are most unwell or aged ≥65 years are at greatest risk of developing complications from neutropenic sepsis (Klastersky et al., 2000, Kuderer et al., 2007). Furthermore, worse symptoms on presentation represent a higher risk (Klastersky et al., 2000). The patients who delay may be more likely to develop septic shock and die (Malik et al., 2001).

There is concern within the literature that patients should be educated to report symptoms of neutropenic sepsis promptly and suggestions are made for improving patient education. The literature described within theme four, does not explore how clinicians communicate with patients about neutropenic sepsis, how they draw on available knowledge to support such consultations, or how successful different approaches to patient communication are, in terms of assisting patients to present early with signs and symptoms of neutropenic sepsis. Furthermore, there is a lack of evidence to underpin patient information about the symptoms of neutropenic sepsis that patients should report urgently.

Chapter Three: Patient-centred communication

3.1 Introduction

An aim of this study was to generate a deep understanding of communication events as shaped by patients, carers and clinicians to explore how such events related to patients reporting of neutropenic sepsis symptoms. Communication within cancer settings should help patients to: deal with bad news and the emotional consequences of a cancer diagnosis, process complicated information, communicate and build trusting relationships with many clinicians, manage uncertainty whilst retaining hope, make treatment decisions and adopt self-management behaviours (Epstein and Street, 2007, Venetis et al., 2009). Despite a large body of research into cancer communication between patients and clinicians, it is suggested this remains the most poorly rated aspect of the doctor patient relationship (Epstein and Street, 2007). In addition, the focus of previous research is on communication between doctors and patients and neglects the impact of other members of the multidisciplinary team, including nurses (Arora, 2003, Marks and Evans, 2005).

Outcome studies tend to focus on patient satisfaction with doctor's communication behaviour, their understanding of information provided, perceived participation during consultations and adjustment to a cancer diagnosis (Epstein and Street, 2007). There is limited evidence to understand the contribution of communication between patients and clinicians to longer term health outcomes such as adherence with treatment and alignment of clinician and patient communication goals such as both parties striving for an outcome of early reporting of neutropenic sepsis symptoms. Theories and models of communication may be usefully applied to the study outlined within this thesis, to assist in understanding why patients may delay presenting to hospital with neutropenic sepsis.

3.2 A framework for patient-centred communication in cancer care

A key issue for communication research, is a paucity of theoretically based frameworks to underpin research methodologies (Arora, 2003, Epstein and Street, 2007). This has resulted in researchers tending to, either develop tools for measuring patient perceptions of physician behaviour, without priori conceptual frameworks or beginning with predefined categories and labelling findings purely on empirically driven factor analysis (Arora, 2003). A model of patient-centred communication in cancer care (PCC) produced by Epstein and Street (2007) on behalf of the National Cancer Institute (NCI) in America, was developed in an attempt to address such issues. This framework includes mediating and moderating factors for patient-centred communication and was developed through a systematic literature review, small qualitative studies and extensive consultations with experts. The PCC framework does not solely focus on outcomes in relation to clinician communication behaviours. Rather the framework encompasses:

> *...the patient, family communication as well as the clinicians and the qualities of the interaction itself that are jointly created by all parties...*
>
> (McCormack et al., 2011, p. 1086)

Crucially, this enables a distinction between assessments of communication encounters from evaluation of these. This is important because what is viewed as a good communication encounter, for example through patient and clinician reports, may not be effective, in terms of health outcomes such as early reporting of neutropenic sepsis. This phenomenon was seen in the field of diabetes, where one study demonstrated that patients who were more satisfied with their care had worse weight control (Kinmonth et al., 1998). Patient-centred communication is described as the facilitator for the delivery of patient-centred care (Figure3.1), which is based on healthcare systems that value and account for individual patient requirements, views and experiences; enabling self-care where desired and optimising relationships between physicians and patients (Epstein and Street, 2007). Patient-centred communication is said to be optimised, where communication occurs through relationships symbolised by reciprocal trust, respect, and commitment rather than through merely imparting information (Epstein and Street, 2007). Examples of patient-centred clinician behaviours and active patient communication behaviours are detailed in table 3.1.

Figure 3.1. **Patient-centred care (Epstein and Street 2007, p2)**

For permission see appendix 2)

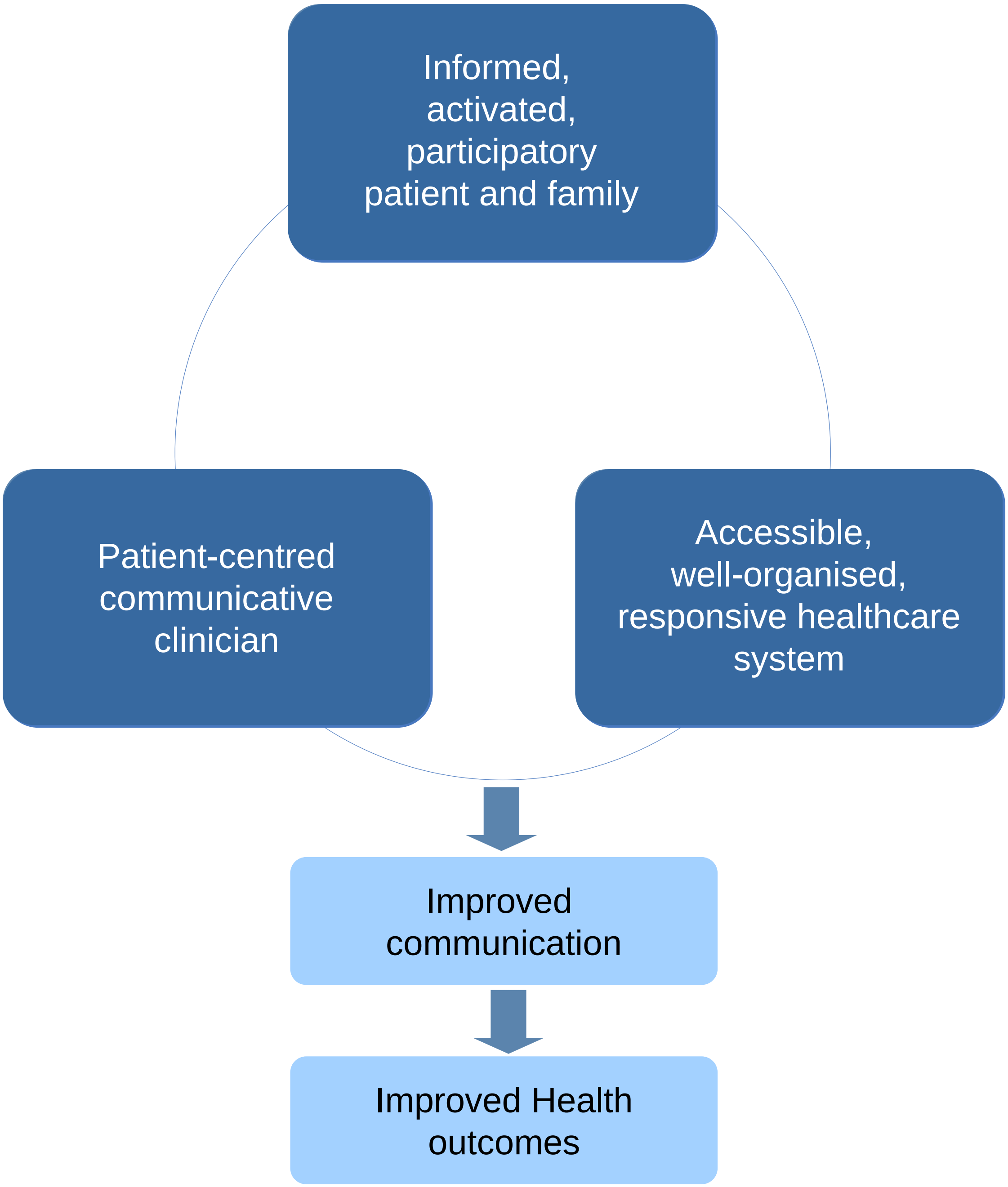


Table 3.1. **Examples of positive clinician and patient communication behaviours (Epstein and Street 2007 p4 and p23). For permission see appendix 2**

Patient-centred clinician	Active patient
Nonverbal behaviours • Maintaining eye contact • Forward lean to indicate attentiveness • Nodding to indicate understanding • Absence of distracting movements (e.g. fidgeting) **Verbal behaviours** • Avoiding interruptions • Establishing purpose of visit • Encouraging patient participation • Soliciting the patients beliefs, values and preferences • Eliciting and validating emotions • Asking about patient and social context • Being honest • Providing sufficient information • Providing clear, jargon-free explanations • Encourage patients to ask questions • Repeat and summarise • Check for patient understanding • Offering reassurance, encouragement and support	**Asking questions** **Communicating assertively** • Offering opinions • Stating preferences • Interrupting if necessary • Sharing beliefs about health • Introducing topics for discussion **Expressing concerns and feelings** • Expressing emotions • Disclosing fears and worries • Noting frustration (Telling one’s health “story “ in the context of everyday life)

3.3 Application of the PCC framework

The PCC model is organised around six domains that represent core mediating functions of patient-clinician communication (figure 3.2) and additional moderating factors between patient-centred communication and health outcomes. If applied to prevention of delayed presentation with neutropenic sepsis, the communication model (figure 3.2) would start with a patient's need to present early with symptoms of neutropenic sepsis. This would lead through mediating pathway A to the six core domains of patient-centred communication between clinicians, patients and carers which include: Fostering healing relationships; Exchanging information; Responding to emotions; Managing uncertainty; Making decisions and Enabling patient self-management. Pathway B suggests the six PCC domains can lead to proximal outcomes such as trusting relationships between patients, carers and clinicians and effective information exchange. This may in turn lead through pathway C to intermediate outcomes, such as ability and motivation to recognise and report early symptoms of neutropenic sepsis, resulting in the completion of treatment at full dose with minimal delays, following a neutropenic episode. Finally, through pathway D overall health outcomes, may include cancer remission and reduced chemotherapy side effect burden. Although these mediating pathways are based on the literature and appear to offer a reasonable explanation for patient delayed presentation with neutropenic sepsis, this is not a certainty because the PCC framework is a hypothetical model, which does not appear to have been tested in clinical practice.

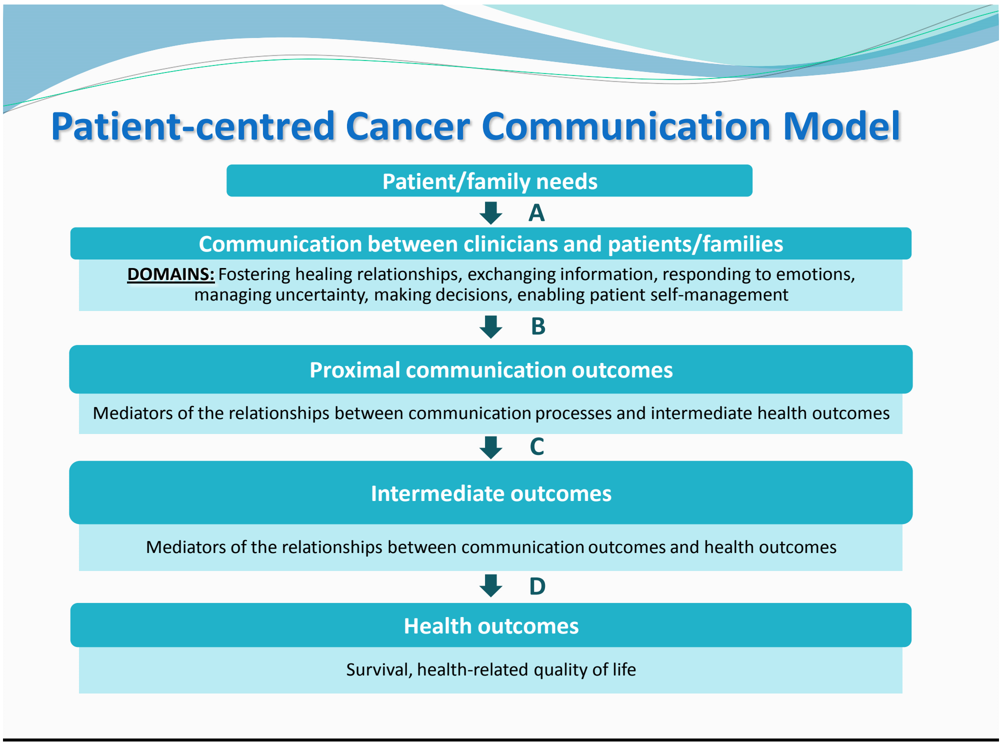
3.3.1 Mediating domains

3.3.1.1 Domain one: Fostering healing relationships

Evidence suggests, that effective healing or therapeutic relationships between patients and clinicians can improve medicine adherence (Pringle et al., 2011). Feeling connected to clinicians who care and understand patients concerns, preferences, beliefs and values is an important aspect of healing relationships (Bakker et al., 2001, Wright et al., 2004, Salander and Henriksson, 2005) and trust, which is an intermediate communication outcome, may be particularly pertinent to non adherence (McCormack et al., 2011). Chronic disease studies have shown that where patients have been educated to participate more actively in consultations with clinicians, they engage more effectively in self-care activities such as blood pressure and blood glucose management (Stewart, 1995).

Figure 3.2. Patient-centred communication conceptual model

(Epstein and Street 2007, p43) For permission see appendix 2



Patient-centred Cancer Communication Model

Patient/family needs

A

Communication between clinicians and patients/families

DOMAINS: Fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, enabling patient self-management

B

Proximal communication outcomes

Mediators of the relationships between communication processes and intermediate health outcomes

C

Intermediate outcomes

Mediators of the relationships between communication outcomes and health outcomes

D

Health outcomes

Survival, health-related quality of life

In addition, when patients and doctors share preferences for control in the relationship, for example where both parties wish the doctor to be more directive, patients can appear more satisfied and report increased doctor endorsement and intention to adhere to treatment requirements (Epstein and Street, 2007).

There is some evidence that patient clinician communication can be affected by race, sex, age and education status (Epstein and Street, 2007). For example, female physicians are said to be more patient-centred in their communication styles, which is associated with greater patient adherence, whereas male physicians are said to often be more directional and authoritarian in consultations with patients (Marks and Evans, 2005). Further, research suggests that some doctors provide patients who are more highly educated with more information (Street, 1991, Waitzkin, 1985) and may provide simpler information to older patients (Roter et al., 1988).

It may be important for patients and clinicians to have shared understanding of each other's roles and responsibilities and discuss and negotiate shared goals (McCormack et al., 2011). Positive communication involves trust, honesty, openness and disclosure from both patients and clinicians. This suggests clinicians should not provide information to patients that is incomplete or misleading (McCormack et al., 2011) about side effects of treatment, such as neutropenic sepsis. For patients this includes their sharing information about health and health behaviours (McCormack et al., 2011).

3.3.1.2 Domain two: Exchanging information

This domain relates to addressing patients' information needs, preferences and knowledge. Sharing information is described by Epstein and Street (2007) as a reciprocal concept where patients share their experiences and understanding of cancer and where clinicians provide information in line with patient preferences. Communication techniques should help patients to understand information provided and to apply it to their own situation (Arora, 2003, Epstein and Street, 2007). Clinicians may not always help patients to achieve this and can under or over estimate patients understanding (Arora, 2003, McCormack et al., 2011). It is suggested patients should not be overwhelmed with information, rather the most relevant facts should be provided following an assessment of understanding and information need (Epstein and Street, 2007, Fallowfield et al., 2006). Importantly, information should be provided slowly, whilst avoiding technical jargon (Arora, 2003, Fallowfield et al., 2006). Facilitating assimilation and recall of information incorporates, assisting patients to understand and retain key information, through repetition of salient points, use of plain English and supportive information resources and through encouraging patients to make notes during consultations (McCormack et al., 2011). Further, it is suggested patients should be assisted if required, to source information from reputable agencies (McCormack et al., 2011).

A number of studies indicate that people with cancer do not always adhere with cancer drug management requirements (Tsang et al., 2006, Partridge et al., 2010, Weingart et al., 2011), suggesting that techniques which can facilitate information assimilation, either may not be effective or are not being applied. Furthermore, the literature relating to neutropenic sepsis described within the literature review chapter (chapter two) of this thesis, suggests patients do not always adhere with advice to present to hospital when they develop symptoms of it (National Confidential Enquiry into Patient Outcome and Death, 2008, Malik et al., 2001, Nirenberg et al., 2004, McKenzie et al., 2011).

Other researchers have also described how some people prefer to know and others prefer to avoid frightening information about cancer. Such differences in peoples' information seeking behaviour are not referred to within the PCC model but may be important to understanding why patients may delay reporting symptoms of neutropenic sepsis to clinicians. Miller's theory (Miller, 1995) of coping strategies employed by patients facing threatening situations, broadly characterises people as monitors, who seek out information and blunters who avoid the same information (Miller and Mangan, 1983, Miller, 1995, Miller, 1998, Ong et al., 1998, Nordin et al., 2002). Miller states the threat and associated anxiety for monitors may be lowered by providing detailed information and emphasising the value of early detection and management. It is further suggested that the attention of blunters should be drawn to risks in a succinct, non threatening way alongside a suggested course of action (Miller, 1995). Other researchers suggest differences in information seeking or avoidance behaviours may depend on circumstance, rather than individual monitoring and blunting traits. Lazarus theory of stress (Lazarus, 1966, Cohen and Lazarus, 1973) suggests that people seek out information, when they feel threatened in order to alleviate fears and increase coping, whilst other researchers suggest patients with cancer can block or filter out information that appears distressing or confusing (McCaughan and McKenna, 2007).

Clinicians are described as often misjudging patients' health beliefs, information needs, feelings and concerns, as well as their likelihood to follow treatment plans (Epstein and Street, 2007). The PCC model suggests that patients and clinicians may have different illness representations of neutropenic sepsis. Illness representations are used to understand and make sense of the cancer experience and are informed by prior experiences, beliefs, others experience, knowledge, psychological status and goals (Epstein and Street, 2007, McCormack et al., 2011). The PCC model supports exploration of patients' illness representations and concerns, through encouragement of verbal expression of such feelings, through employment of patient-centred communication skills detailed in table 3.1 (page 59). These include open ended questions that address psychological aspects of communication; empathy and active listening (Epstein and Street, 2007, Arora, 2003).

3.3.1.3 Domain three: Responding to emotions

According to the PCC model fostering healing, co-operative relationships when providing information to patients, should assist them to make informed decisions to present early with symptoms of neutropenic sepsis (Donovan and Blake, 1992, Arora, 2003, Epstein and Street, 2007). The PCC model also suggests emotions may negatively impact on successful information delivery. According to research 23-40% of cancer patients experience psychological distress, which is a barrier to effective communication (Fallowfield et al., 2006) and can lead to poor adherence (McCormack et al., 2011). Emotions may be expressed by patients and carers in various ways during consultations with clinicians, through for example fear, humour, nervousness, anxiety, sadness or fatalistic views (Epstein and Street, 2007). Patients are likely to have heightened emotions, when information about neutropenic sepsis risks is conveyed to them, as this usually coincides with attempts to make sense of a new cancer diagnosis and the need for chemotherapy treatment and a perceived potentially life threatening situation. Emotions may consequently, impact on patients ability to process information about neutropenic sepsis (Treacy and Mayer, 2000). Unfortunately though, clinicians may miss emotional cues and focus more on physical aspects of health (Epstein and Street, 2007) rather than eliciting psychological issues, through sensitive questioning and responding with constructive help and empathy (Epstein and Street, 2007).

3.3.1.4 Domain four: Managing uncertainty

Little research exists on managing uncertainty in cancer care and the PCC model focus is on prognosis, rather than presentation with chemotherapy side effects. Never the less Mishel's uncertainty and illness theory (Mishel and Braden, 1988, Mishel, 1990) which informs the PCC model provides a useful framework to explore uncertainty experienced by patient participants going through chemotherapy. Mishel and Braden, (1988) defines uncertainty during illness as:

> *…the inability to determine the meaning of illness related events. It is the cognitive state created when the person cannot adequately structure or categorise an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and / or is unable to predict outcomes accurately*
>
> (Mishel, 1988, p. 225)

Mishel's theory (Mishel and Braden, 1988, Mishel, 1990) positions uncertainty as affected by the stimuli frame, cognitive capacity and structure. The stimuli frame relates to patients' ability to produce a mental schema of events (Mishel and Braden, 1988) which if unclear increases uncertainty. Symptom profile; event familiarity and event congruence are incorporated within the stimuli frame. The symptom profile, in relation to this study would refer to the extent patient participants are helped to predict normal chemotherapy symptom patterns. Event familiarity would refer to the extent health events, important to neutropenic sepsis are recognised by patients as familiar. Event unfamiliarity during complex cancer events can be significantly related to uncertainty ($p<0.05$) (Mishel and Braden, 1988) which may be important to delayed reporting of neutropenic sepsis. Event congruence might refer to consistency between actual events and expected scenarios (Mishel and Braden, 1988) during chemotherapy and episodes of neutropenic sepsis.

Cognitive capacity, the second influence to affect uncertainty, relates to the ability to process information about neutropenic sepsis. The third influence, structure providers, is the resources that assist patients to determine symptom patterns, event familiarity and increase event congruence and thus reduce uncertainty. Structure provider elements include credible authority, education and social support. Credible authority incorporates patient-centred communication behaviours, which Epstein and Street (2007) indicate should reduce and help patients to manage uncertainty. Important relationship elements known to reduce uncertainty include trust and confidence in clinicians. Educational structure relates to providing information to reduce patient uncertainty, at the required educational level, so accounts for those with lower cognitive ability taking longer to process and construct meanings (Mishel and Braden, 1988). The third structure provider identified by Mishel and Braden (1988) to reduce uncertainty is social support provided by other patients and carers.

Research carried out in primary care, suggests that patient confidence can reduce where clinicians express clinical uncertainty (Epstein and Street, 2007) and uncertainty in cancer patients has been shown to lead to emotional distress and a sense of poor control over health and quality of life (Dunn et al., 1993, Andreassen et al., 2005). Epstein and Street (2007) suggest that uncertainty can be exacerbated through information overload and that patient-centred communication should moderate uncertainty and importantly assist patients to manage it. There is some evidence that cognitive behavioural techniques can help patients monitor for cancer symptoms (Epstein and Street, 2007). The PCC model suggests that provision of context in terms of the likely impact of neutropenic sepsis for individual patients and an agreed plan for dealing with uncertainty may be helpful (McCormack et al., 2011).

3.3.1.5 Domain five: Making decisions

This domain refers to patients making decisions in relation to treatment options. This suggests most patients prefer making these decisions in partnership with clinicians. As with the managing uncertainty domain, the principles appear pertinent to patients who are required to make decisions about presenting to hospital with symptoms of neutropenic sepsis. Application of the PCC model suggests patients who develop symptoms of neutropenic sepsis may assimilate information obtained from various sources and weigh up the pros and cons of taking particular courses of action, before making a final decision. This domain suggests decision making by patients, who have symptoms of neutropenic sepsis may be optimised by effective information exchange and their beliefs and understanding of the information provided, including the rationale for presenting early. Furthermore, additional literature, not included in the PCC model also suggests that emotions (Fallowfield et al., 2006) and cognitive impairment, cited in the literature as “chemo brain” referring to memory loss and poor concentration (Mitchell and Turton, 2011) may impact on decision making.

3.3.1.6 Domain six: Enabling self-management

The enabling self-management domain draws from the primary care chronic disease management model and is a relatively new area for cancer care (Epstein and Street, 2007, McCormack et al., 2011). This domain focuses on enablement through collaboration between patients and clinicians, to identify and solve problems, take action and set goals in relation to health. This requires a shift in focus from treating patients as passive recipients of information to active participants in their care. More specifically, the PCC framework suggests that enablement of early reporting of symptoms of neutropenic sepsis, may require adoption of patient-centred communication skills by clinicians to identify and remove obstacles to self-management and to increase patient autonomy and the ability to self-care, whilst making informed choices (Epstein and Street, 2007). This domain draws on three theories including: self-efficacy theory (Bandura, 1977); self-determination theory (Ryan and Deci, 2000) and the 5 A’s for patient-centred counselling (Glasgow et al., 2003).

Self-efficacy theory (Bandura, 1977) is the most commonly cited theory to understand self-management. This describes personal motivation to change behaviour, driven by a belief in ability to achieve the change. Bandura (Bandura, 1977, Bandura, 1994) states people will undertake required action, if they believe themselves competent and self-efficacy is associated with persistence to succeed. Importantly, Bandura says people, who believe they are incapable of achievement may view required behaviours as a threat and avoid performing these. Self-efficacy is determined by cognition of four information sources or influences (Bandura, 1994). *Enactive attainments,* the most influential information source suggests achievement or mastery of a new behaviour; *vicarious experiences* or modelling relates to learning from others' experiences and *verbal persuasion* facilitates belief in capability to carry out a required action. *Physiological* or *somatic and emotional state* relates to an association between visceral arousal of negative stress reactions and reduced self-efficacy and ability to perform.

Self-determination theory, like self-efficacy theory relates to motivating patients to draw upon inner resources to act in healthy ways. A core difference is a perception by Bandura of perceived confidence as a mediating role to achievement. Self-determination theory is more concerned with a natural inclination towards intrinsically motivated behaviours which interest and satisfy, as opposed to attempts by others to extrinsically motivate behaviours through external goals that may not be of interest. Deci and Ryan (Deci and Ryan, 2000, Ryan and Deci, 2000) identify three basic innate psychological needs of competence, autonomy and relatedness that should be fulfilled in order to be self-determined. Competence refers to a need to experience mastery; relatedness to a need to feel connected to others and experience reciprocal caring relationships and autonomy, to feeling in control and responsible for one's life. It is suggested all three needs should be met to be self-determined although; some become more important at different times and depending on circumstances and culture. If these three needs are supported, positive outcomes are said to include encouragement of intrinsically motivated behaviour and integration of extrinsic motivation. If needs of competence, relatedness and autonomy are not met, negative outcomes are said to include declining motivation, performance and health (Deci and Ryan, 2000, Ryan and Deci, 2000).

Cognitive evaluation theory informs self-determination theory and suggests intrinsic motivation may be enhanced by enabling competence and autonomy through positive feedback and rewards whereas negative feedback is said to reduce intrinsic motivation (Deci, 1975, Deci and Ryan, 1985). Organismic integration theory also informs self-determination theory, and suggests a continuum along which extrinsically motivated behaviours may become autonomised. Externally regulated behaviour is proposed as associated with least autonomy because this is driven by rewards or outside stipulations. The most autonomous extrinsically motivated behaviours are said to be achieved through integrated regulation by fully internalising externally motivated behaviours as core to personal beliefs and needs (Deci and Ryan, 2000). Importantly, organismic integration theory indicates internalisation of externally motivated behaviours is more likely when the need for relatedness is met (Deci and Ryan, 1985).

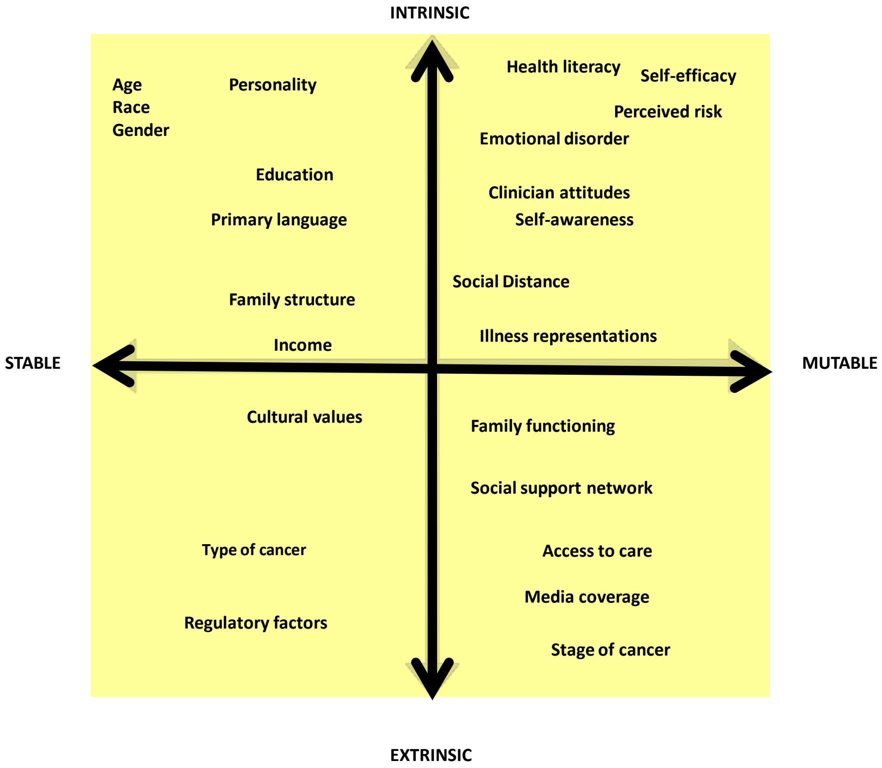
In relation to the PCC self-management domain Epstein and Street (2007) say that competence may be instilled through provision of clear guidance, access to resources and development of appropriate skills. Further, promotion of autonomy may instil competence, which may reduce where clinicians are more instructive (Ryan and Deci, 2000, Epstein and Street, 2007). Importantly autonomy does not mean being independent from others (Deci and Ryan, 2000). PCC behaviours which may promote this include providing simply put and jargon free advice and adoption of recall prompting techniques like repeating and summarising key points and asking patients to articulate their understanding of advice provided (Epstein and Street, 2007). Autonomy may further be promoted through exploring patients' uncertainty about taking health promoting action and providing different options to achieve the same outcomes by, for example, assisting patients to understand when they should call chemotherapy helplines, or to think about different options for getting to hospital, should this be required. Training patients to have useful discussions with clinicians, based on the patient's agenda may also promote autonomy (Epstein and Street, 2007). Relatedness incorporates clinicians and patients developing connected, trusting relationships which should encompass advocacy, through clinicians being available when needed to help patients navigate the healthcare system. In the case of neutropenic sepsis, this would mean equipping patients to access high quality information and 24-hour acute oncology services, designed to facilitate fast identification and treatment of neutropenic sepsis.

The third theory is the "5A's" (Assess, Advise, Agree, Assist, Arrange) model of behaviour change which aims to help patients develop personal action plans (Glasgow et al., 2006). For enabling symptom reporting in relation to neutropenic sepsis, the "5A's" model would suggest, clinicians should *assess* patients beliefs and knowledge about this; *advise* on the risks of delayed presentation and the benefits of early presentation; *agree* on goals for early presentation; *assist* in identification of potential barriers to early reporting, develop strategies to overcome these and finally *agree* and *arrange* follow up support.

3.3.2 Moderators

Mediating aspects of patient-centred communication incorporated within the PCC model that may impact on patients' adherence with reporting symptoms of neutropenic sepsis, have been described. In addition, factors identified by the PCC framework, may moderate relationships between communication and timely reporting of neutropenic sepsis (figure 3.3). This two dimensional model presents moderators along the vertical axis, that range from being intrinsic (native) or extrinsic (external) to patient, family and clinician relationships. The horizontal axis relates to the extent to which a moderator is stable (difficult or impossible to change) or mutable (modifiable). It is important to recognise, the moderators on the left hand side of the grid may be less open to change and could represent barriers to adherence. Moderators on the right hand side of the grid may be more malleable to change and responsive to patient-centred communication, that may result in patients experiencing increased agency and self-efficacy. Epstein and Street (2007) describe complexities associated with extrinsic moderators and the multiple layers within, which health communication occurs and which lead to different outcomes dependent on the situational context. Illness related factors, social situations, healthcare systems and cultural influences are all contextual elements.

Figure 3.3. **Intrinsic and extrinsic moderating factors for PCC and health outcomes (Epstein and Street 2007, p51). For permission see appendix 2)**



3.4. Chapter conclusion

The research outlined within this thesis seeks to understand why patients delay presenting to hospital when they develop neutropenic sepsis. The PCC model was identified rather than only self-efficacy theory as the most suitable framework to apply to this study. Firstly, the enabling self- management domain incorporates self-efficacy theory; and each of the following principles identified by NICE (2007), as relevant for promoting behaviour change and which may be important to self-management of neutropenic sepsis symptoms:

- Understanding of benefits and consequences of actions
- Personal relevance of a required behaviour
- Positivity about behaviour
- Self-efficacy
- Descriptive norms or copying positive behaviours from others in a similar position

- Promoting personal and moral commitment
- Goal setting
- Identifying potential barriers and ways to deal with these

(NICE, 2007, p. 10)

Secondly, the PCC framework allows for the complexities of communicating with patients who have cancer. Finally, this incorporates a possible mediating effect of relatedness achieved by clinicians, who connect with patients emotional responses to cancer and cancer treatments and who engage with their social networks in relation to health outcomes. Consequently, the PCC model will be drawn upon within this thesis, to inform initial areas of research inquiry and to compare and contrast findings. It is anticipated this will assist in the identification of reasons for patients presenting late to hospital, when they develop neutropenic sepsis. Furthermore, this study may generate knowledge regarding clinical applicability of the research based, hypothetical PCC model and identify particular mediating and moderating factors important to facilitating patients reporting of neutropenic sepsis symptoms to clinicians.

Chapter summary:

Associations between clinician and patient communication behaviours and health outcomes are poorly studied. Most research focuses on the impact of communication on a limited range of intermediate health outcomes, such as patient satisfaction with their interactions with clinicians, which may not equate to behaviour change or actions by patients. Epstein and Street (2007) sought to overcome such problems through the development of the PCC framework. They applied available evidence to develop six patient-centred communication domains they believe mediate health outcomes through complex pathways. Suggested proximal outcomes include trust and effective information exchange. This in turn may lead to intermediate health outcomes such as improved advocacy and quality of medical decisions; patient knowledge; emotional self-management; therapeutic alliances; family and social support; ability to self-care; access to care and improved patient agency through self-efficacy, empowerment and enablement.

The PCC model appears most suitable to apply to this study because it is cancer focused. It also incorporates an association between patients' knowledge, beliefs, behaviour and the principles for behaviour change. This was identified as important within a NICE evidence review (NICE, 2007). Furthermore, the PCC model includes a suggested association between the clinician and patient relationship and adherence that may be important to the reporting of neutropenic sepsis. This model as described by Epstein and Street (2007) will consequently inform early data generation in the current study and explore possible mediators and moderators of patient-centred communication. This model will be applied to compare and contrast study findings and to identify any important factors relating to patients delaying their presentation to hospital with neutropenic sepsis. It is suggested that the application of the PCC framework to the findings from this study, may improve understanding of any benefits or constraints when applying the PCC model to clinical practice.

Chapter Four: Research methodology

4.1 Research questions

The grounded theory research approach required initially starting with a broad area of inquiry related to patients with neutropenic sepsis delaying reporting to hospital. Other areas of inquiry emerged as important as data analysis progressed. The research question was:

Why do some patients delay reporting to hospital with signs and symptoms of neutropenic sepsis, and what assists patients to present earlier to reduce the effects of neutropenic sepsis?

During initial data collection the following areas of inquiry were explored through observations and interviews:

1. How patients, carers and clinicians communicate about risks of neutropenic sepsis.
2. How clinicians prepare patients and carers to manage risks of neutropenic sepsis.
3. What affects intentional and non-intentional patient non-adherence to reporting signs and symptoms of neutropenic sepsis.

4.2 Study design

A qualitative research design was employed for this study in order to explore new areas of inquiry, allow complex social phenomena to be understood and rich insightful data to be collected (Green and Thorogood, 2004). Ethnography was the methodological approach for data collection and grounded theory was applied to direct data collection and analysis, in order to develop a theory that arose from the data. Data were gathered through non-participant observation and in-depth interviews which included longitudinal and retrospective elements. Data were analysed using the constructivist grounded theory approach described by Charmaz (Charmaz, 2006) which focuses on social processes, interaction and meaning.

The research design allowed, from the earliest point of data collection, an ability to gradually refine and focus the enquiry and emerging analytical ideas. This was through comparison, immersion in the data and alternating between this and the research field. This process was assisted by a flexible approach of a co-ordinated but not sequential research process. This included theoretical sampling, where the emerging data analysis was used to drive the identification of areas of inquiry and the participants to be included within the next stages in the research process. The grounded theory approach enabled development of conceptual categories, which were reconstructed to develop a theory grounded in the data. This would provide insight into how patients developed an understanding of risks of chemotherapy induced neutropenic sepsis and the complexities related to associated patient self-management.

The research was undertaken in a large London Cancer Centre and involved patients with a diagnosis of breast cancer who were at particular risk of developing neutropenic sepsis during chemotherapy according to available guidelines. This included the study of those receiving chemotherapy regimens with ≥20% risk; age ≥65 years or with metastatic disease. Participants included patients admitted to hospital with neutropenic sepsis, their carers (identified by participating patients as the relative or friend who provided them with most support during chemotherapy) and the clinicians (medical and nursing staff) who interacted with them about this treatment side effect. Observational and interview data were collected and analysed until data saturation was reached; i.e. when nothing new came out of the data and categories appeared fully developed with regards to properties and dimensions.

4.2.1 Steering group and user involvement

The impetus for this research evolved from patient and clinician feedback based on personal experiences. Clinicians who provided chemotherapy services were concerned that patients often delayed presenting to hospital with neutropenic sepsis. Additionally, local patient surveys and focus groups identified a need to improve information and support for those undergoing chemotherapy. A chemotherapy patient working group, who had previously been involved in chemotherapy service development work, endorsed the importance of research to establish why patients delay contacting the hospital when they develop neutropenic sepsis. Carers were further engaged in this study through a carers’ reference group, previously established within King’s College London. Academic colleagues and clinicians involved in chemotherapy service delivery were also invited to join the steering group set up for the research presented here. The final steering group consisted of patients and carers with experience of neutropenic sepsis, an oncologist, specialist chemotherapy and acute oncology cancer nurses and a patient education expert. The group met on two occasions and terms of reference and minutes of these meetings are enclosed in appendix 3. The steering group meetings focused on assisting in refining the research question and discussing the intermediate findings. Further meetings to present the final study findings and to explore the design of an intervention study will be held following submission of this thesis.

4.3 Ethnography

Ethnography stems from anthropology which researches culturally rooted beliefs and customs within small communities (Savage, 2000). Utilisation of ethnographic methods allowed sharing in the patient experience and an understanding of the complexities related to patient self-management of neutropenic sepsis. Insight was gained into how patients developed an understanding of the risks of chemotherapy induced neutropenic sepsis and how such perceptions impacted on their behaviour and actions. Brewer (Brewer, 2000) offers the following definition of ethnography:

> *Ethnography is the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally*
>
> (Brewer, 2000, p. 10)

Although not participating directly in the research field ethnographic methods, which included non-participant observation and in-depth interviews, enabled familiarity with activities associated with communication and action in relation to neutropenic sepsis. The ethnographic approach also enabled an understanding of patients', carers' and clinicians' behaviours, beliefs and meanings in relation to it. Employment of ethnographic methods enabled the generation of rich, reflexive data to demonstrate the cultural context of experiences and actions related to patients delayed presentation to hospital with neutropenic sepsis and how this was constructed between researcher and participants.

4.4 Grounded theory

Ethnographic research can generate large amounts of data which can be difficult to manage and make sense of. Grounded theory developed from ethnography can specifically enhance ethnographic data analysis through structuring ongoing focused data collection and analysis. This is achieved through promoting closeness to the data, making connections between events and through the study of basic social processes (Glaser and Strauss, 1967, Charmaz and Mitchell, 2001, Charmaz, 2006, Timmermans and Tavory, 2010). Grounded theory includes the following non-linear processes described by Charmaz and Mitchell (2001) as common to all forms of grounded theory:

1. Simultaneous data collection and analysis.
2. Pursuit of emergent themes through early data analysis.
3. Discovery of basic social processes within the data.
4. Inductive construction of abstract categories that explain and synthesise these processes.
5. Integration of categories into a theoretical or conceptual framework that specifies causes conditions and consequences of the process (es).

(Charmaz and Mitchell, 2001, p. 160)

The grounded theory approach to data analysis has been successfully applied to recent other ethnographic research in cancer care. These include an ethnographic study (Tuffrey-Wijne et al., 2009) which explored experiences of people with learning disabilities who had cancer and informative PhD research (Eliasson et al., 2011) which explored cancer patients intentional and non intentional adherence with taking oral chemotherapy drugs. An overview of grounded theory from its roots in positivism and a justification for applying the constructivist approach, developed by Cathy Charmaz, to this study (which explored why patients delayed presenting to hospital with neutropenic sepsis) will be provided. This next section is in part informed by attendance at an interactive four day grounded theory summer school in Italy during 2012. This course was run by world leaders in grounded theory, including Professor Massimiliano Tarozzi; Professor Janice Morse, Professor Maria Mayan and Juliet Corbin. Juliet Corbin has provided ongoing advice in relation to this study through SKYPE communication.

4.4.1 Objectivist grounded theory

Qualitative methods have been heavily criticised by positivists who cite lack of scientific controls, unsystematic, overly subjective methods and findings that cannot be generalised as key problems. In response to this, some qualitative researchers adopted a positivist approach to their research by attempting to remove researcher effect from data collection and quoting rich text as standalone interpretations of data (Hammersley and Atkinson, 2007). Humanistic (naturalism) ethnography and original grounded theory, developed by sociologists Glaser and Strauss (Glaser and Strauss, 1967) supposes that text may be interpreted by the researcher without recourse to their own influence on data generation and analysis.

Grounded theory epistemology was developed at a significant time in social science research, within the University of California Nursing School by Glaser and Strauss in the 1960's. Barney Glaser had undergone quantitative training and original grounded theory was based on positivism which represented the inductive discovery of truth and the neutral researcher. The Discovery of Grounded Theory (Glaser and Strauss, 1967) aimed to legitimise and raise qualitative research to be on a par with the quantitative paradigm, through the addition of rigour and systematic processes. The Glaser and Strauss (1967) approach aimed to discover theory which emerges from and is grounded in qualitative data rather than forcing findings into existing theory (Glaser and Strauss, 1967). An understanding of meanings of experiences is gained through breaking up the data and reconstructing these. Data analysis involves staying close to the data to develop concepts rather than description. Concepts provide a language for talking about the emerging data and are described by Corbin and Strauss as:

> *Words that stand for ideas contained in data. Concepts are interpretations, the products of analysis*
>
> (Corbin and Strauss, 2008, P. 159)

The grounded theory approach enables exploration of processes and actions and categories through which these are organised. Charmaz (2006) describes processes as:

> *..unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between. The temporal sequences are linked in a process and lead to change* (Charmaz, 2006, p. 10)

Corbin and Strauss (Corbin and Strauss, 2008) describe processes as a complex continuing interplay of multiple actions, interactions and emotional reactions that often occur in response to a problem and usually in an attempt to overcome it. Research participants may not be directly aware of these responses and they may also not be immediately obvious to researchers (Corbin and Strauss, 2008). Corbin and Strauss also point out that actions, interactions and emotional responses will vary greatly depending on contextual factors and the way a problem is perceived by the individual.

Glaser and Strauss (1967) state that theory emerges initially out of conceptual categories and their conceptual properties grounded in the data, which then become increasingly refined throughout the research process. Glaser and Strauss state:

> *A category stands by itself as a conceptual element of the theory. A property, in turn, is a conceptual aspect or element of a category*
>
> (Glaser and Strauss, 1967, p. 36)

Properties are components that characterise and define concepts and are further developed in terms of dimensions which delineate variance within a property. The second element of theory are *hypotheses or generalised relations among categories and their properties* (Glaser and Strauss, 1967). Together these elements provide an overarching theoretical picture that represents each case included within a study.

The purist grounded theory approach is inductive, in that researchers do not seek to test preconceived ideas or a prior hypothesis. Rather, Glaser and Strauss (1967) state that through a systematic approach, the neutral researcher discovers and constructs a supposedly unbiased theoretical representation of the truth. Constant comparison is core to this process and requires the researcher to continuously move back and forward between the data and analytical thoughts to combine data collection, coding and analysis. Ideas are generated about the data and the data is employed to change and develop ideas. This is achieved through focused inquiry and theoretical sampling, to identify participants most likely to assist with exploration of emerging ideas from the data.

Glaser and Strauss's grounded theory, along with post-modern ethnography, were heavily influenced by Chicago symbolic interactionism (Blumer, 1969) and the philosophy of pragmatism (Mead, 1956). Both of these consider that knowledge develops from action and interaction and focuses on emerging concepts from the data (Corbin and Strauss, 2008). This would suggest an interpretive approach, although original grounded theory (Glaser and Strauss, 1967) was criticised, as was the humanistic ethnographic approach, for its alignment with the positivist paradigm and a realist ontology considered to relate to a naive realism. This was because it assumes that objective realities can emerge from qualitative research that are not influenced or constructed by researchers or respondents (Denzin and Lincoln, 2005). A risk is the positivist approach may not represent subjective influences of participants' knowledge, experience and meaning or the social world they inhabit. It may further give too much weight to researcher interpretation and authority. This may create inaccurate data representation that does not account for the extent a researcher can be neutral and purely inductive.

During the 1960s the positivist paradigm was in stark contrast to the modernist movement, which was aligned with interpretive qualitative research approaches (Denzin and Lincoln, 2005). In the 1980s Glaser and Strauss parted company and carried out separate research activities. Glaser stayed true to the original positivist principles of his grounded theory approach and Strauss joined forces with Corbin. Together, Strauss and Corbin produced Grounded Theory in Practice (Strauss and Corbin, 1997), which was interestingly although objectivist, more aligned to a relativist ontology than the Glaser and Strauss' method. Strauss and Corbin (1997) attempted to provide greater structure and guidance for researchers wishing to use the approach, and focused more on new procedures for data analysis rather than emphasising the comparative method (Charmaz, 2006). Strauss and Corbin's work was criticised by Glaser (1992) as being overly prescriptive and analytical, forcing data into preconceived categories. Glaser stated this was not grounded theory; rather a new methodology had been developed by Strauss and Corbin (Glaser, 1992). Corbin, following the death of Strauss, has continued to develop grounded theory but is now less prescriptive than in early versions of the method.

Key concerns about objectivist grounded theory that remain today, include a view that data is broken up and treated as cold and separate from researcher influence and participants lived experiences; thus preventing insight into their worlds and meanings. Researchers choose how to tell the story, how to represent the data, what to leave in and leave out. Their own values and experiences are also likely to influence analysis (Charmaz, 2006). Charmaz states that objectivist grounded theory separates:

> *...the experience from the experiencing subject, the meaning from the story and the viewer from the viewed*
>
> (Charmaz and Mitchell, 2000, p. 521)

4.4.2 Constructivist grounded theory

A key development in the evolution of qualitative research methods from a positivist to an interpretive paradigm was the introduction of a constructivist approach which has been applied to this study. This evolved through postmodern, reflexive ethnography and within grounded theory, work carried out by Kathy Charmaz, a student of Glaser and Strauss. Charmaz's work challenges the assumptions of objectivity within the positivist paradigm and returns to the original grounded theory of examining processes. Charmaz's constructivist approach moves grounded theory further towards a relativist ontology. That assumes existence of multiple perspectives on reality and a subjectivist epistemology that views knowledge as co-created by researchers and participants. Charmaz and Mitchell, (2000) state:

> *"…people create and maintain meaningful worlds through dialectical processes of conferring meaning on their realities and acting within them"*
>
> (Charmaz and Mitchell, 2000, p. 521)

Glaser and Strauss (1967) consider they discover theory which emerges from the data whereas the constructivist stance takes a more interpretive approach to grounded theory, aligning this with its original influence of symbolic interactionism which accentuates meaning but is open to the existence of multiple realities. Charmaz (2000) points out that data and analysis are a construction of reality; they form an interpretation of this rather than the absolute truth or an exact picture and one greatly influenced by socio-political influences. Importantly, constructivist grounded theory answers critics by being clear about the place of the researcher within the research as a reflexive co-constructer of knowledge who puts participants' stories at the heart of the final theoretical interpretation (Charmaz 2006). The ethnographic approach and the grounded theory method followed within this study (that seeks to understand why patients do not report symptoms of neutropenic sepsis) allowed for a reflexive constructionist approach. Corbin, within the core grounded theory text, (Corbin and Strauss, 2008) specifically aligns their approach with constructivism and stresses; she understands there are multiple realties waiting to be discovered:

> *I agree with the constructionist viewpoint that concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and themselves*
>
> (Corbin and Strauss, 2008, p. 10)

Rather than providing a set of research directives for undertaking grounded theory, Corbin and Strauss (2008) suggest these are applied as a set of qualitative procedures and analytical tools to aid analysis and stimulate thinking. Charmaz (2000) too considers grounded theorists are able to use analytical tools flexibly to explore subjective experiences without the constraints of the positivist approach. This is the position taken within this study which seeks to understand why patients delay reporting symptoms when they develop neutropenic sepsis.

4.5 Research process

4.5.1 Recruitment

4.5.1.1 Ethical permission

Ethical approval was obtained from the NRES Committee, London (REC reference 11/LO/0488) and local research and development (R&D) permission to carry out the study was also secured (appendix 4). The main ethical considerations for this study related to potential risks concerning participant coercion, distress and anonymity or researcher identification of a concerning clinical issue. Experience of working in cancer care and the training and support available through the associated National Institute of Healthcare Research (NIHR) Training Fellowship enabled the appropriate management of ethical issues raised during the research process. The Head of Nursing for Cancer at the research site agreed to act as a contact person for anyone who may have concerns regarding the study and in case of any clinical concern identified during the research. There was a risk that clinicians would feel coerced to participate in this study, particularly as senior members of staff or potential gate keepers approved the research. Clinicians may, furthermore, have altered their behaviour in response to being observed during the study and may have felt under inspection, judged or disempowered. Prior research experience ensured that permission was sensitively secured for undertaking non-participant observations. Further, undertaking research outside of the usual researcher work place was expected to reduce the pressure to participate in the study.

It was carefully explained to participating clinicians that the purpose of the research was not to judge and that data collected would remain anonymous. Participants were informed that data would be held in a secure data base and that anonymised quotes and pseudonyms would be used in the final report. Names or other identifiers would not appear within records used to document observations, interviews or papers reporting the project. Details of the participating hospital have been removed from ethical documentation detailed within the appendices of this thesis and this information will not be included in other papers or reports. In addition, no individuals will be recognisable from the data that are presented in either this thesis or subsequent publications. It was confirmed that all participating clinicians understood they were under no obligation to participate in the study, that no-one in their organisation would know if they did or did not take part in the study, and that their participation or non-participation would not affect their employment. Once recruited, consent was reconfirmed with clinicians at each stage of the research process.

Patient and carer participants may also have felt under pressure to participate in the study or to consider their privacy was compromised. Furthermore, patients may have felt too unwell to participate in the research, particularly around the time of an inpatient admission for neutropenic sepsis. Consequently, it was agreed that the clinical team would advise whether a patient was sufficiently well to be approached to participate. Potential participants suitable for inclusion were offered flexible times for the interviews. Patient and carer consent was reconfirmed throughout the data collection process; and they were informed their care would not be compromised should they decide not to participate in the study or to withdraw from it at any point. There was also a risk that sensitive issues about the disease or treatment may be raised during the research process and that clinical issues may be identified. The agreement was that in such cases patients would be referred to the appropriate clinical teams who were in a position to arrange additional support.

4.5.2 Sampling strategy

The grounded theory approach required data to be collected in a flexible, co-ordinated but not sequential fashion. The research process was inductive. The PCC model was used to inform early stages of data collection rather than to identify hypotheses. Knowledge generated from emerging data and questions arising from developing categories focused the direction and order of ongoing data collection.

The research site was a breast cancer unit within a London Cancer Centre. The data collection methods involved four participant samples, and longitudinal and retrospective elements. The longitudinal sample was required to capture data related to information exchange about neutropenic sepsis and the impact of this on symptom reporting. The longitudinal element was informed by data collected from a pilot patient (which will be elaborated within chapter five) and included recruiting women who had breast cancer prior to them starting chemotherapy and following them through treatment. They were initially observed – through non-participant observation – when they were provided with information about neutropenic sepsis during outpatient chemotherapy consent appointments with doctors and separate chemotherapy nurse consultations. Short informal interviews were conducted immediately following observed appointments with participating clinicians, patients and carers. This was to explore feelings and views in relation to neutropenic sepsis and the consultation. In addition and as part of the retrospective element, separate in-depth interviews with patient participants who took part in non-participant observation were carried out following completion of chemotherapy.

The retrospective sample was required both to explore carer and clinician' experience of neutropenic sepsis and also that of patients. This was because it could not be predicted if those who participated in the longitudinal element would experience symptoms of neutropenic sepsis. Planned in-depth interviews were conducted with the remaining three participant samples: (1) patients admitted to hospital with neutropenic sepsis; (2) carers of patients who developed symptoms of neutropenic sepsis; and (3) clinicians who interacted with patients in relation to neutropenic sepsis. The aim was to gather rich data, to illuminate emotions and behaviours within the context of the lived experience of communication about neutropenic sepsis and patient delays (Charmaz, 2006). The purpose of attaining data from different participants (including patients, carers and clinicians) from different data sources such as interviews and observation, and at different times was to gain a comprehensive understanding of patients' and carers' preparation for managing episodes of neutropenic sepsis. Perceptions of risks or perceived confidence and willingness in managing these episodes and actions taken when neutropenic sepsis occurred were also explored.

Data attained in this way were to provide different perspectives of the same phenomena, which is understanding and beliefs about neutropenic sepsis and its attendant risks, so these could be compared. This would be enhanced further, as data were gathered from participants with shared experiences in relation to neutropenic sepsis, in order for different perspectives on a story to be gathered. Confidence in findings may be improved where parallel conclusions (developed through challenging with disconfirming cases) are drawn from these different data sources. This also poses different threats to validity, so together may lead to improved validity of the study (Charmaz, 2006). Different data sources helped to build a meaningful picture; as Glaser and Strauss state:

> *Different kinds of data give the analyst different views or vantage points from which to understand a category and to develop its properties; these different views we have called slices of data.*
>
> (Glaser and Strauss, 1967, p. 65)

The purpose was to develop theory not to prove population representativeness through gathering high volumes of data (Glaser and Strauss, 1967, Charmaz, 2006). Patients and clinicians considered of most interest to the study were to be initially, recruited and theoretical sampling, through constant comparison, would evolve using emerging findings to direct the next steps of data collection. Ideas and hunches or hypotheses were followed up through focused inquiry and sampling participants with characteristics most likely to assist in exploring and elaborating identified concepts further. Focused inquiry fits with the funnel approach of ethnography to gradually build and develop a focused picture of patient understanding and reporting of neutropenic sepsis as proposed by Hammersley and Atkinson (2007).

Clinicians, including oncologists and cancer nurses attended study briefing sessions and written consent was obtained from all participants prior to observations and interviews. Outpatient clinics and inpatient wards were attended and e-mail contact kept with clinicians to identify potentially suitable patients for inclusion in the study. Patients were selected purposively through asking the clinical team to identify those with required characteristics. The clinical team approached and explained the study to suitable patients and asked for permission to introduce them to the researcher. The researcher next provided these patients with more detailed information and encouraged them to ask questions, before obtaining informed consent. Carers were recruited via patients enrolled in the study. When clinicians who worked outside of the oncology team became of interest, the area clinical leads were initially approached to gain approval and an introduction to suitable candidates. Six information sheets were produced for the different groups of participants involved and an example is presented in appendix 5.

4.5.3 Participants

4.5.3.1 Patients

It was initially intended to recruit patients to this study with a variety of cancer diagnoses to explore their understanding and experiences of neutropenic sepsis. There is though a lack of empirical evidence related to why patients do not present to hospital with neutropenic sepsis. Consequently, it was decided to concentrate on one patient group comprising different socio-psychological backgrounds and the clinicians, who interact with them in relation to neutropenic sepsis, rather than to dilute or complicate study findings by including a range of cancer types. Breast cancer patients were identified in ASCO (Smith et al., 2006), EORTC (Aapro et al., 2006, Aapro et al., 2011) and MASCC (Klastersky et al., 2000) guidelines as a particular group at risk of developing neutropenic sepsis during chemotherapy. This is mainly due to the chemotherapy drugs prescribed which pose a $\geq$20% risk for neutropenic sepsis (Smith et al., 2006, Aapro et al., 2006, Aapro et al., 2011). It was also established that clinicians provided information about recognising and acting upon neutropenic sepsis to this group of patients. Furthermore an adequate sample of patients at risk of developing this could be recruited. Women with a diagnosis of breast cancer and receiving chemotherapy were therefore recruited to the study. The aim was to explore issues related to initial communication about neutropenic sepsis and any subsequent decision to present to hospital for treatment.

As previously mentioned, the longitudinal element included patients who allowed observations of clinical encounters where chemotherapy was first explained to them, and who further participated in informal interviews immediately afterwards to discuss the witnessed events. The purpose was to explore how information about neutropenic sepsis was provided and the patient's immediate thoughts, feelings and understanding about this. Follow up in-depth interviews after the final chemotherapy treatment, enabled exploration of issues identified during observations and analysis and to identify and discuss any symptoms of neutropenic sepsis that developed during treatment, and patient response to these.

In order to ensure knowledge was gained from those who had experience of neutropenic sepsis, audio recorded interviews (offered face to face at home/hospital or by telephone) were also carried out with a retrospective patient sample, who had been admitted to hospital with neutropenic sepsis. These interviews enabled an exploration of the patient's perception of information given about neutropenic sepsis, their beliefs about this condition, any admission to hospital and delays in the identification and treatment of neutropenic sepsis.

4.5.3.2 Clinicians

Clinicians were observed providing information to patients and carers about neutropenic sepsis during the longitudinal study element. Clinicians also took part in audio recorded in-depth interviews (face to face hospital interview or by telephone). Initially interviews were carried out with clinicians who provided information about neutropenic sepsis to patients. These were confined to immediate members of the breast cancer team including chemotherapy nurses, breast care nurses and doctors. In line with the grounded theory approach other clinicians were recruited as they became of interest. The purpose of interviews was to explore clinicians' experience and perceptions of patient safety management in relation to neutropenic sepsis. Initially, the inquiry focused on clinicians' views about how risks of neutropenic sepsis should be explained to patients and carers, their experiences and perceptions of the process of risk communication and their understanding and feelings about patient interpretation and actions in relation to risk and safety. As the research progressed other issues became of interest and data gathered through observation and informal interviews could be further explored with the clinicians concerned.

4.5.3.3 Carers

For the purpose of this research, carers were defined by patients as the person who provided them with the most practical and emotional support during their chemotherapy treatment. This was either a relative or a friend. Carers participated in the longitudinal element (observation and informal interviews). One audio recorded in-depth interview (offered face to face at home/hospital or by telephone) was also carried out with carers to explore their understanding of the risks of neutropenic sepsis and their role and experience in identifying and reporting symptoms of the condition to hospital staff. As data collection progressed, it became obvious that carers of patients who had developed symptoms of neutropenic sepsis would be of most relevance to the study as they could talk about experience of identifying and reporting these to clinicians.

4.6 Data collection methods

4.6.1 The longitudinal element: Non-participant observation and Informal Interviews

Charmaz (2006) recommends following patients over time as perceptions may change. This allows for follow up of previously identified issues, making connections between witnessed consultations and later interviews and developing relationships with participants which can lead to improved disclosure (Charmaz, 2006). A longitudinal, prospective element was therefore included within this study, involving non-participant observation of initial chemotherapy information sessions and in depth interviews at the end of treatment (offered face to face at home / hospital or by telephone). The design of the longitudinal element was informed through recruitment of a pilot patient which will be described in more detail within the following chapter. For the remaining patients who took part in the non-participant observation element, this involved them being accompanied to two key consultations before chemotherapy treatment started and where neutropenic sepsis was discussed. The first observed consultation was between doctors, patients and carers, where written patient' consent for chemotherapy treatment was obtained. The second observed consultation was the pre-treatment information session with a chemotherapy nurse that was dedicated to informing patients about the imminent treatment and potential side effects of chemotherapy, including neutropenic sepsis.

Non-participant observation aims to generate data through watching and listening to what people naturally do and say (Hammersley and Atkinson, 2007). The aim was to identify a picture of how patients were informed about neutropenic sepsis in terms of what was happening, who was involved, where it happened and how. The focus was on discovering behaviours, roles and thinking within the context of micro-influences related to participants and witnessed situations and the macro cultural and institutional conditions from which these arise. Observation promoted closeness to the data of naturally occurring conversations related to neutropenic sepsis that occurred within the natural environment of the outpatient clinics and the chemotherapy day unit. The focus was on the social construction of neutropenic sepsis, the purpose being to share in the experience of consultation interactions and to talk to participants about how they interpreted these witnessed events and the social meanings behind these.

Conversations between clinicians, patients and their carers who accompanied them during these appointments were observed and digitally audio-recorded. Hand written field notes were kept which contained details of where and when consultations took place, who were involved or present as well as impressions of the consultation (including general atmosphere and mood, physical positioning of participants, striking actions or behaviours, non-verbal behaviours and interruptions). An observation grid was developed and used, which related to the six patient-centred cancer communication model domains identified within chapter three: Fostering healing relationships; Exchanging information; Responding to emotions; Managing uncertainty; Making decisions and Enabling self-management. As part of observation work, patients and carers (where present) were engaged in joint informal interviews immediately following the observed planned consultations. Participating clinicians were also interviewed informally on the same day as observed consultations.

Informal discussions initially guided by the PCC domains, observation notes and recall of witnessed behaviours, explored participants' perspectives. This was to gain a deeper understanding of witnessed behaviours and how understanding of neutropenic sepsis was co-constructed. Discussions were held with patients about their experience of witnessed interactions, their perceptions of chemotherapy symptoms and their feelings about pending chemotherapy treatments. Clinicians were asked how they thought patients received information about neutropenic sepsis and might cope with reporting chemotherapy symptoms. Patients were encouraged to speak about any prior communications related to reporting of neutropenic sepsis, which may illuminate observations further. At the end of the observation period, similarities and differences between observations and notes of what to look out for or explore in more detail at the next observation were documented within observational field notes.

4.6.2 The retrospective element: In-depth Interviews

In-depth interviewing in grounded theory is distinguished by continual reflection and increasingly focused inquiry as research progresses. Reduced topic areas were covered as irrelevant categories were cast aside or important categories were fully developed in terms of properties and dimensions (Charmaz, 2006). This approach assisted with overcoming a common mistake made within grounded theory when researchers do not develop an in depth picture of the social processes studied. This was important for this research as it was likely participants, including the clinicians, would not be consciously aware of deep rooted emotional or psychological reasons why patients do not present to hospital with neutropenic sepsis. At the International Grounded Theory Summer School attended by the researcher, Janice Morse (an international expert in grounded theory) spoke about good grounded theory exploring below the surface whilst remaining in touch with the surface, so that these kinds of deep rooted thoughts can be related by researchers to actions. Juliette Corbin also pointed out that:

> *....analysis requires getting into the heads of participants, taking the role of the other and trying to identify what it is that they are telling us or doing through their actions and interaction*
>
> (Corbin, 2012, Grounded Theory Summer School)

An aim consequently, was to “get inside the heads of participants” to elicit responses that represented, as far as possible, their experiences, meanings, views and beliefs. Interviews were digitally audio-recorded and semi-structured to allow participants to speak about issues that were important to them and to tell their own story about chemotherapy and neutropenic sepsis. Interview guides or discussion topics initially informed by the PCC model were referred to during interviews to ensure all topics were considered and these became increasingly focused as the research process progressed (appendix 6). The same questions were asked in different ways to address possible differing participant interpretation. Participants were offered the choice of a telephone or face to face interview for their convenience and it was anticipated some might feel able to speak more openly over the telephone (Novick, 2008). Multiple interactions with observed patients resulted in closer relationships and deeper exploration of their feelings and experiences during interviews (Charmaz and Mitchell, 2000). This was also the case for observed clinicians where observation and informal interviews generated insights which were explored further with them during in-depth interviews.

Observation, informal discussions and in-depth interviews enabled an insider perspective of the context and culture within which clinicians talked about the risks of neutropenic sepsis with patients and carers and allowed exploration of participants' thoughts, feelings, beliefs and understandings about neutropenic sepsis.

4.7 Analysis

4.7.1 Analytical tools

4.7.1.1 Constant comparison

Constant comparison is core to grounded theory and there are no apparent differences between objectivist and constructivist approaches. Key authors in the field advocate comparing "everything everywhere" including:

- Comparison of emerging data with data collected from the outset not after data collection is completed.
- Participant perceptions, stories, actions and experiences.
- Participant responses at differing times.
- Events with events.
- Identification of relationships between concepts and categories.

(Charmaz, 2000, p. 515, Charmaz, 2006, p.23)

Constant comparative analysis was central to the coding process within this study which explored why patients delayed reporting to hospital with neutropenic sepsis. This involved constant movement between the data and developing concepts to compare those coded in the same way in order to develop and refine these to core categories which related to areas of interest and concern for participants. Comparative analysis assisted in becoming theoretically sensitive to the data through working closely with it and asking probing or sensitising questions. This was to explore further what was happening, what was seen as important by participants and to stimulate further related areas of inquiry. Barney Glaser (Glaser, 1978) states the researcher should focus from the start on identifying the basic social and psychological processes. The data was subsequently interrogated to establish how processes were constructed through action, how they manifested, which ones were important and to whom, who controlled them and how, how they were spoken about, how perceptions and actions changed and who viewed processes as fundamental or marginal (Charmaz, 2006).

Further analytical techniques used included examining the data closely and picking out words that seemed significant, writing down different meanings and checking or validating these with the text. Techniques like the “flip flop technique” (Corbin and Strauss, 2008) were used to stimulate analytical thinking by comparing and contrasting extremes of dimensions. This technique involved thinking about a concept and what the opposite perspective might be, in order to generate new questions to ask of the data. Systematic comparison was employed to explore how dimensions within categories differed. Language expressed, emotions, metaphors and similes and disconfirming cases were examined and particular attention paid to anything puzzling and for red flags which indicated areas for further inquiry. Phrases like “that never happens”, “that could not happen”, “it’s always been like”, may indicate participants’ biases, assumptions or beliefs and these were identified as areas for further exploration (Corbin and Strauss, 2008).

4.7.1.2 Theoretical sampling

Areas of inquiry, initially informed by the PCC domains and participants thought to be of early interest who might explain why patients delay presenting to hospital with neutropenic sepsis were initially included. This became increasingly focused through theoretical sampling employed to follow up on ideas and hunches. Glaser and Strauss (1967) describe theoretical sampling as:

> *The process of data collection for generating theory whereby the analyst jointly collects codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory...*
>
> (Glaser and Strauss, 1967, p. 45)

Emerging findings were used to direct next steps in data collection through observation or interviews with participants considered most likely to assist in exploring identified concepts further. Theoretical sampling often involves many data collection sources and documentation also became important. Charmaz (2000) points out that theoretical sampling assists the researcher to:

- define properties of categories
- identify the contexts in which they are relevant
- specify the condition under which they arise, are maintained and vary
- discover their consequences

(Charmaz, 2000, p. 519)

This process encourages questioning about what is known and the certainty of this and what inquiry routes to pursue. Throughout the research process hypotheses were developed in relation to patients delaying going to hospital when they developed neutropenic sepsis. Ideas about what was happening in the research field and possible meanings were explored through constant comparison of data from new participants and by returning to previous data sources. As the inquiry became increasingly focused, all witnessed events did not require documentation and interviews deepened and narrowed to focus on information required to develop categories. Some categories emerged as more important and required further exploration and development than others and some not relevant to the study were discarded (Glaser and Strauss, 1967).

4.7.1.3 Analytical memos and diagrams

Analytical memos and diagrams were used throughout the research process to assist with the constant comparison process. These facilitated and documented progressive analytical ideas and thoughts which informed further areas of inquiry. Memos and diagrams encouraged immersion in the data from the outset. This assisted in becoming theoretically sensitive to the data through gaining an early understanding of possible meanings behind witnessed actions. Memos and diagrams assisted in conceptual thinking, acted as an audit trail of analytical thoughts and ensured that ideas were not lost as data collection and analysis progressed towards theory development. Diagrams encouraged taking a step back to think logically about the content and direction of analysis, as well as potential relationships between the data. Memos were written about each interview and observation and described early ideas and categories. Charmaz (2006) advocates not fussing with early memo writing, rather letting thoughts flow onto paper without attention to grammar or spelling. This produced early simple and awkward memos and diagrams but ones which captured spontaneous and often insightful thoughts and sensitising concepts or questions for further inquiry. Sensitising concepts describes a way of thinking deeply about the data and asking questions of it to explore what lays beneath the text to develop a representative, meaningful reconstruction (Glaser and Strauss, 1967, Blumer, 1969). As Corbin suggested at the Summer School, attention was paid to what was really happening around patients not reporting neutropenic sepsis and the significance of that.

Memos and diagrams were reviewed and developed as the research progressed and became increasingly sophisticated and conceptual as analysis moved towards theory development. A list of sensitising questions and analytical ideas were informed by memos, immediate post interview analytical thoughts, and annotations generated during the coding process. Memos were compared with each other, which often raised further questions and stimulated generation of another memo (Corbin and Strauss, 2008). Memos and diagrams were discussed with Juliette Corbin, during Skype calls and memos were sorted as described by Charmaz (2006) to assist in developing theoretical connections:

- Sort memos by the title of each category
- Compare categories
- Use your categories carefully
- Consider how their order fits the logic of the categories

- Create the best possible balance between the studied experience, your categories and your theoretical statements about them

(Charmaz, 2006, p. 117)

4.7.2 Application of the literature and the patient-centred cancer communication model

Theoretical sampling encourages the researcher to reflect on biases and predetermined ideas. Opinions differ amongst grounded theorists on exploration of the literature before or during the data collection and analysis period. Glaser and Strauss (1967) caution against referring to the literature until the analytical categories have emerged:

> *An effective strategy is, at first, literally to ignore the literature of theory and in fact on the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas. Similarities and convergences with the literature can be established after the analytic core of categories has emerged*
>
> (Glaser and Strauss, 1967, p. 37)

Other grounded theorists including, Corbin and Strauss (2008) and Charmaz (2006) consider the grounded theory process is open to simultaneous literature review and that it is impossible to bracket prior knowledge and views. Rather, the constructivist approach encourages reflexive thinking about how the literature impacts on research. For this study a scoping review of the literature (chapter two) was carried out that demonstrated that some patients present late to hospital with symptoms of neutropenic sepsis. This was associated with poor clinical outcomes and increased cost to the health service. What is not clear from this review is how patients and carers are educated and equipped to recognise and report symptoms of neutropenic sepsis, or why some patients who develop it, present late. Following a review of the PCC model, described within chapter three it was anticipated this would assist with the inquiry process to better understand this phenomena. In alignment with recommendations by Corbin and Strauss (Corbin and Strauss, 2008) the PCC framework was applied to inform questions for initial in depth interviews and observations and during analysis to compare and contrast with emerging findings, whilst taking account of different culture and work practices within America where the PCC framework was developed.

Grounded theory requires researchers to have as few preconceived ideas as possible in order to be open and sensitive to the data. Consequently, it was application and reflection on prior knowledge to inform and enhance data generation and analysis, rather than to drive the analysis, that was important. Prior knowledge included the PCC framework, other literature which emerged as important as analysis progressed and reflection on experiences of working within chemotherapy services. The PCC domains were applied to the grounded theory process as follows:

4.7.2.1 Domain one: Fostering healing relationships

This domain informed exploration of roles and relationships formed between patients and clinicians. It included both parties' perceptions of these, their nature and potential impact on adherence with early reporting of symptoms of neutropenic sepsis. Specifically, during in depth interviews and observations attention was paid to the kinds of relationships demonstrated between patients, carers and clinicians. Exploration focused on how patients and clinicians behaved during witnessed interactions. It also included how goals related to early reporting of neutropenic sepsis were negotiated and agreed and to what extent patients' concerns and beliefs about reporting of neutropenic sepsis were identified, explored and addressed. Interest was taken regarding any differences in healing relationships between different types of patients and clinicians to focus ongoing enquiry.

4.7.2.2 Domain two: Exchanging information

This domain was applied to explore how information was provided to patients and their carers about chemotherapy and the effects of this on reporting symptoms of neutropenic sepsis. Attention was paid to how involved patients and carers were in discussions about neutropenic sepsis, in terms of being given the opportunity or encouraged to ask questions and to seek clarification. Consideration was paid to the pace and amount of information delivered, the words used to describe neutropenic sepsis, any tips or advice provided to assist with early presentation, the degree to which information was personalised and how clinicians checked patients' understanding of this chemotherapy complication. Interest was taken in regard to patients' and carers' understandings and beliefs and perspectives of neutropenic sepsis including the risk of this happening to them, how equipped they felt to deal with it and their awareness of the risks involved should neutropenic sepsis occur. Further, exploration focused on any tensions in risk management for patients who developed symptoms of neutropenic sepsis, to gain an understanding about how they made sense and prioritised these.

4.7.2.3 Domain three: Responding to emotions

In relation to the responding to emotions domain, attention was paid to emotions experienced by patients and their carers related to chemotherapy side effects and in particular neutropenic sepsis, how these were responded to by clinicians, patients and carers and how they affected reporting of neutropenic sepsis.

4.7.2.4 Domain four: Managing uncertainty

The communication literature suggests it may be advisable for clinicians to manage patient uncertainty about when to call chemotherapy helplines through explaining typical scenarios in terms of recognising, reporting, diagnosing and treating neutropenic sepsis. This domain informed exploration of the concept of uncertainty, the extent of this, as well as any attempts to manage it through communication enquiry, provision of scenarios and illustration of actions to take should symptoms of neutropenic sepsis arise.

4.7.2.5 Domain five: Making decisions

The making decisions domain directed attention to understand how clinicians equipped patients to make decisions about reporting symptoms of neutropenic sepsis and the thought processes employed by patients to make such decisions. Attention was paid to how information was framed in terms of clarity around severity of symptoms to report, any scenarios provided and checking of understanding. Interest was taken in any phenomena that may have affected decision making to make contact with the hospital in the event of neutropenic sepsis symptoms developing, such as impaired cognition, emotional influences and home commitments.

4.7.2.6 Domain six: Enabling self-management

Attention was paid to how clinicians worked with patients and carers to develop self-management strategies to identify and report neutropenic sepsis and the ability, confidence and commitment of patients to seek appropriate care when required. Observation included the content of information provided, the extent to which communication styles were facilitative or instructive, when information was provided and any support provided between chemotherapy treatments. Techniques employed by clinicians were observed for, that may assist patients to develop self-management strategies, such as agreeing goals for early presentation with symptoms of neutropenic sepsis, identification of potential barriers and the development of strategies to overcome these. Attention was paid to the extent clinicians checked patients’ understanding, clarified misconceptions and rehearsed action to take should symptoms of neutropenic sepsis occur. In addition, moderators, which may impact on patient’ engagement with self-management to report neutropenic sepsis were identified through constant comparison and theoretical sampling.

4.7.3 Preparing data for analysis

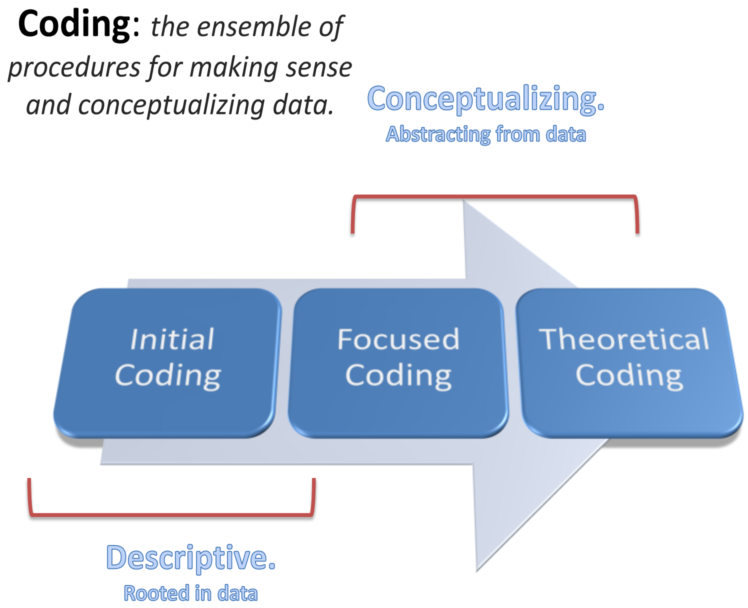
Data for analysis consisted of observation notes, a reflective diary and interview transcripts. Organisation of data was an important precursor to data analysis. Paper work was ordered chronologically and NVIVO software (version 9) was used to store, manage, index and organise the data electronically. Interviews and observational notes were transcribed as soon after the events as possible and included details of dates, times, places and people involved in observations and interviews. Early interviews and observations were transcribed to assist with familiarity of the data and for later transcripts this was carried out by a paid transcriber. All data recordings were listened to and for initial observations and interviews this was at least twice. This facilitated checking all data transcribed to ensure accuracy, continued closeness to the data and accurate coding. Prior to carrying out follow up observation or interviews, previous analytical notes and recordings were revisited. This refreshed the memory and allowed deeper exploration of topics discussed in earlier interactions.

4.7.4 Coding

Coding within grounded theory should retain the integrity of participant accounts and facilitate reflection (Charmaz, 2006). The coding process described by Charmaz (2006) and core to constructivist grounded theory was applied and is illustrated within figure 4.1 (Tarozzi, 2012). Three types of coding were applied to the data. Initial coding was descriptive and grounded in the data. This was followed by focused and theoretical coding carried out at a conceptual level. This process was assisted by pilot work, reflections from the field and discussions with academic supervisors.

Figure 4.1. Constructivist grounded theory coding process. Presented at Grounded Theory Summer School (Tarozzi, M., 2012)

For permission see appendix 2



4.7.4.1 Initial open coding

Analysis started with open coding which required immersion in the data and retaining an open mind. Each line of interview and observation text was carefully examined and any interesting emerging actions or events labelled. The principles of open coding were followed for the first 10 data sets as described by Charmaz (2006):

- Remain open
- Stay close to the data
- Keep your codes simple and precise
- Construct short codes
- Preserve actions (ing)
- Compare data with data
- Move quickly through the data

(Charmaz, 2006, p. 49)

This generated an initial 80 codes which were grounded in or close to the data and reflected and described actions. This prevents researchers making conceptual inferences too early in data collection and analysis (Charmaz, 2006). Moving quickly through the data can spark analytical thinking so documented reflexive thoughts included why particular codes were identified, how personal biases and experience influenced interpretation of data and why particular sensitising questions were identified (Charmaz, 2006). Initial codes were labelled with analytical descriptions, where possible using in-vivo codes which represented participant' views and often included direct participant quotations. NVIVO was used to allocate text to identified codes and the annotation function used to document analytical notes and sensitising questions. These contributed to analytical thinking and memo building. The first ten coded data sets were ordered under the six PCC domains which assisted with early analytical thinking. This represented a combination of emergent and a-priori approaches, as in keeping with the grounded theory method the intention was not to fit findings to the analysis. Constant comparison was used to review data sources to ensure that all data was coded in the same way and nothing had been missed. If, for example, a new issue was discovered at the sixth data source, previous data sources were checked for the same phenomena.

4.7.4.2 Focused coding

Once the initial ten data sources had been coded using open coding, focused coding was carried out which involved a paper based system. Initial codes were printed onto paper and cut into individual strips to create a coding map. Paper strips were arranged on a table and codes that seemed to relate to each other were clustered together to represent early categories (figures 4.2 and 4.3). This assisted analytical thinking about what categories were about and to label these conceptually. Initial codes, which essentially described the same process, were joined together or collapsed. This resulted in the development of early conceptual categories and properties of these. This represented a move away from the patient-centred communication model which had assisted with earlier analytical thinking. Six categories were identified as more conceptual and reflective of the emerging data. Theoretical sampling and constant comparison were employed to develop early categories further. In order to reflect and develop the theory regular breaks were taken from data collection to become immersed in the data and to ensure the same information was not merely collected from subsequent participants. Rather, breaks in data collection enabled time to write memos, draw diagrams and develop categories and their properties and dimensions. This enabled identification of the categories which could either be developed further or discarded. There was time to carefully develop theoretical sampling strategies and sensitising questions to probe deeper into emerging important issues related to patients delaying reporting to hospital with neutropenic sepsis. Suggested hypotheses were quickly developed to be tested against prior and emerging data. As the analysis progressed relationships could be tested between emerging categories and properties (Glaser and Strauss, 1967). As the research moved further towards theory development and there was enough data to understand categories and properties, the category dimensions were developed as suggested during the summer school by Professor Janice Morse, “through thinking about these people act like this and these people act like that.” Essentially, this enabled identification of participant’ characteristics or moderators that appeared more associated with delayed reporting of neutropenic sepsis.

Figure 4.2. Focused coding, early categories and properties

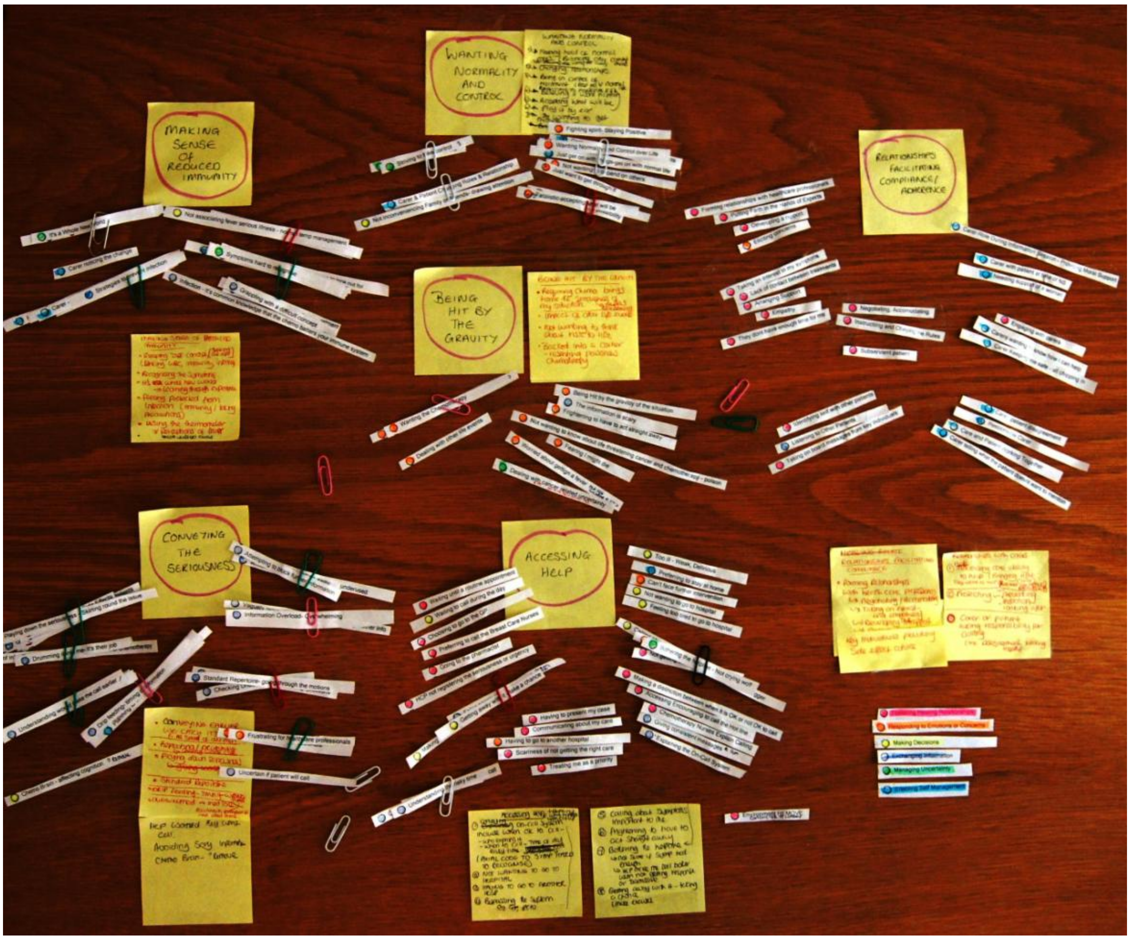


Figure 4.3. Focused coding, early categories and properties

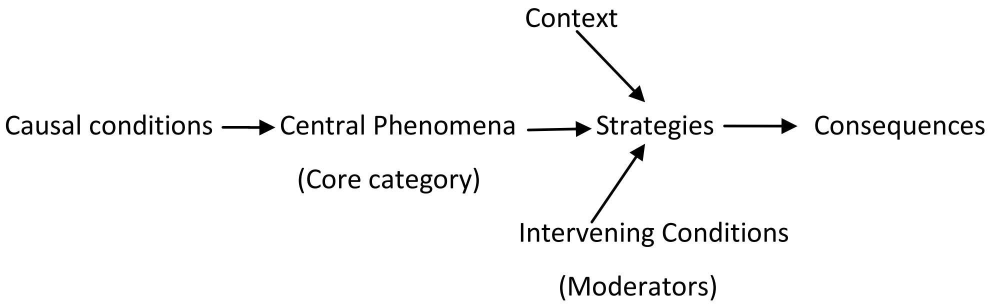
4.7.4.3 Theoretical coding

As the analysis progressed, a theoretical model was generated through establishing explanatory connections related to processes, between categories developed through focused coding, through representative text. The sophisticated process of theoretical coding was assisted by a succession of analytical diagrams developed to think about and illustrate possible relationships between categories. Corbin and Strauss (2008) suggest axial coding is applied to make these connections and bring fractured data back together through asking on a conceptual level, when, where, why, who, how and with what consequences. Axial coding is seen as too prescriptive by Glaser and constructivists who consider it may force artificial connections between categories (Charmaz, 2006). Rather, constructivist grounded theorists view coding as being more flexible and creative. As previously mentioned, analytical tools should earn their way into the theory building process to fit rather than force a relationship (Charmaz and Mitchell, 2000).

Glaser developed 18 theoretical coding families (Glaser, 1978) to assist in weaving the deconstructed or fractured story back together rather than forcing and complicating it. Theoretical codes can sharpen the theoretical analytical edge and can assist with identifying and understanding temporal and structural ordering and thus processes (Glaser and Strauss, 1967).The grounded theory to explain why patients delay reporting neutropenic sepsis was developed through application of a theoretical coding model developed by Morrow and Smith (1995) to developing categories (figure 4.4). This facilitated questioning processes in the data in terms of:

(a) The causal conditions that trigger participants' responses to the threat of neutropenic sepsis.
(b) The central phenomena or core explanatory category, which provides a conceptual explanation for why patients and carers adopt particular coping strategies.
(c) The contextual conditions that show how systems and processes might influence how patients respond. Contextual conditions are identified by asking where, when and how the central phenomena /core explanatory category happens and with whom.
(d) The intervening conditions or factors that might influence different participant responses. (Intervening conditions are termed moderators within the patient-centred communication model).
(e) The strategies or reactions and behaviours patients adopt to deal with the central phenomena / core category.
(f) The consequences of strategies employed by patients to cope with the threat of neutropenic sepsis.

Figure 4.4. Model framework (Morrow and Smith 1995; p305)
For permission see appendix 2



As categories developed, theoretical coding also involved validating proposed connections through searching data for confirmatory and contradictory accounts and by adding to categories that needed further filling out in terms of dimensions or properties. Disconfirming accounts amended and extended the data. The coding process continued until categories were filled out in terms of properties and dimensions. This is termed data saturation which for grounded theory signals that new data will not add to the development of identified categories or identification of new ones. This does not mean stopping data collection when the researcher is hearing the same stories, rather:

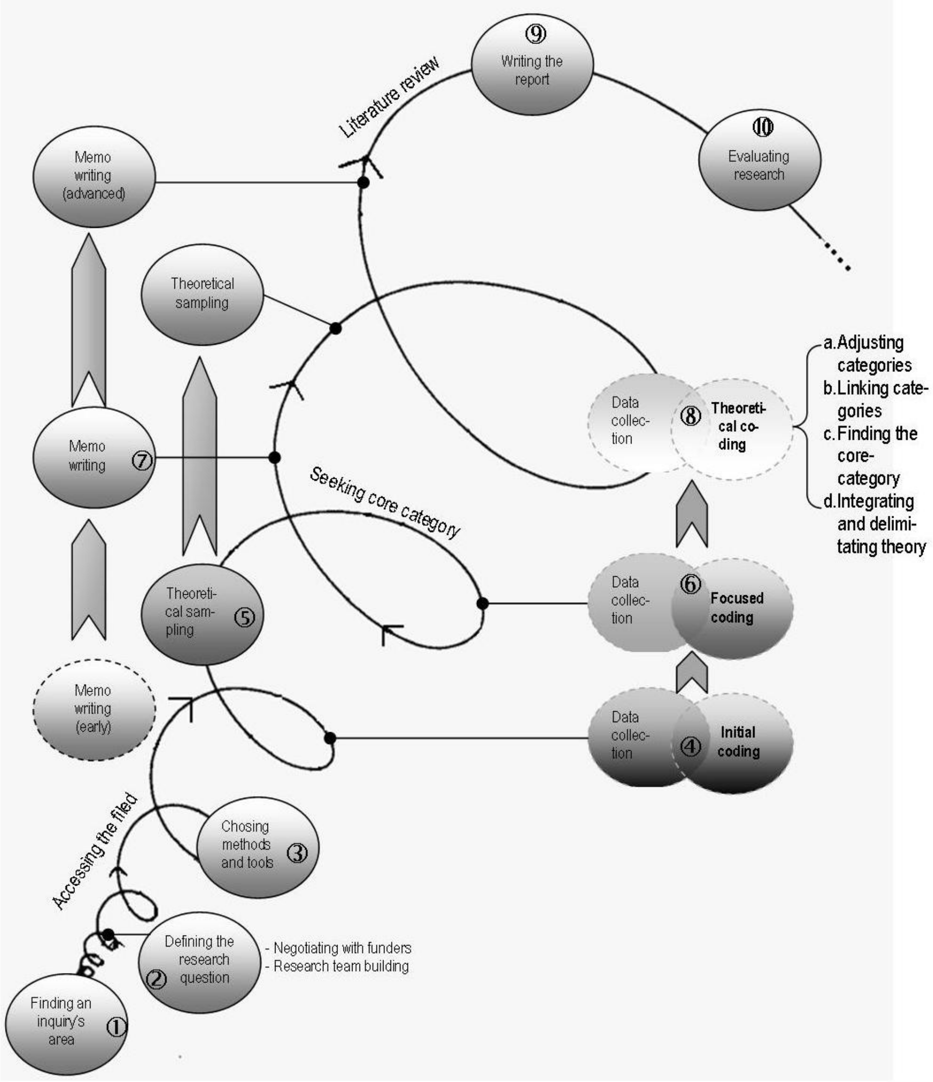
> *Categories are 'saturated' when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your theoretical categories…..it is not the same as witnessing repetition of the same events or stories…*
>
> (Charmaz, 2006, p. 113)

Analytical tools including, constant comparison, the flip flop technique and memos and diagrams continued to be employed to integrate and delimit the theory around an identified core explanatory category to which the other categories were related. The core category meets the criteria set out by Juliette Corbin at the Summer School as an abstract concept that represents the complete picture as a process (e.g. Playing down the seriousness) or a phenomenon (e.g. fear). Although abstract it should remain grounded in the data (Glaser and Strauss 1967). Corbin and Strauss (2008) states the core category should be applicable and identified in each case studied and that other categories should interact with it without forcing the relationship. Finally, the theoretical framework should be applicable to study other situations to generate the theory further. The completed model represented a theoretical representation of the research findings.

The linear but non sequential process employed to develop the grounded theory is illustrated within figure 4.5 which was presented by (Tarozzi, 2012) at the Grounded Theory Summer School in Italy. This demonstrates the inductive nature of grounded theory with continuous movement between data collection and analysis, whilst applying analytical tools to gradually develop the emerging theory.

Figure 4.5. **Che cos^{1}è la grounded theory.Roma:Carocci (Tarozzi, 2008).**

For permission see appendix 2



4.8 Research rigour

Published grounded theory studies are sometimes criticised for paying lip service to using the approach, rather than using this accurately. This is because some researchers apply grounded theory techniques to analysis, rather than embedding the research process throughout the whole study (Tarozzi, 2012). Research rigour was in part achieved through acquiring the necessary knowledge and skills to become an ethnographer and grounded theorist. Training commenced prior to undertaking this research and new skills and knowledge were robustly applied to this study. This was achieved through wide reading of relevant literature, attendance at the Grounded Theory Summer School in Italy in 2012 and follow-on support throughout the thesis from Juliet Corbin.

Positivist researchers have criticised qualitative approaches for lacking methodological controls core to scientific research. Postmodern qualitative researchers counter these criticisms by arguing that qualitative research gets nearer to reality than the quantitative approach. Qualitative research can lead to a more accurate representation of social worlds which are changing entities that are created, recreated and perceived by people within them. Qualitative researchers do not take data as factual and separate from the people it relates to. Rather, they generate knowledge of social worlds through voices of participants within them who are best understood in their own familiar environments. Data, including interviews and observation notes reflected experiences of delayed attendance to hospital with neutropenic sepsis. This is because they were gathered and analysed within systematic, rigorous, transparent and trustworthy research processes which are inbuilt to post modern constructivist research.

Reflexivity is presented as the key solution to what is termed the crisis of representation of qualitative researchers, who align themselves with the positivist paradigm (Hammersley and Atkinson, 2007). Qualitative researchers are part of the social world under study and work in close proximity to the research field. Consequently, data and analysis were in part informed by clinical experience, identity, background, cultural beliefs, views and the authority and relationships built with participants. The aim of reflexivity was to ensure transparency about role and effect on data generation and analysis. Diaries written whilst undertaking the data collection, and memos about data interpretation were used to explore how prior held thoughts, views, clinical experiences, beliefs and authority might impact upon the data collection and analysis. Critical reflection particularly focused on presence in the research field and perspectives on the data collected and how these related to a position as an experienced chemotherapy nurse. Importantly, a key role of academic supervision during the development of this thesis was to support reflexivity.

Research rigour is also made visible within this thesis through demonstration of researcher integrity. This is achieved through showing how field relationships were forged and how data saturation was achieved, by making clear problems encountered through the research process and including, within research reports, the process for data categorisation and interpretation. This was further achieved through considering alternative explanations for data organisation and providing numerous rich and contradicting participant quotations to allow the reader to make their own interpretations. This demonstrated data complexity through not positioning this as a neat representation of the social world under study and looking for and discussing negative cases, to challenge and explore assumptions more deeply.

Chapter summary:

Data were collected from participants including women who were prescribed chemotherapy for breast cancer, their carers and clinicians. They participated in non-participant observations of chemotherapy information sessions and in-depth interviews. Ethnography was employed for data collection. Constructivist grounded theory (Charmaz, 2006) was applied to direct data collection and analysis and to develop a theory that was grounded in the data. The ethnographic approach facilitated understanding of the culture within which neutropenic sepsis was managed through observation and participants telling their stories in their own words. This was assisted by the iterative process of grounded theory which encouraged deep exploration of emotions, beliefs and perceptions. This generated data which when reconstructed illuminated experiences and taken for granted constructs that informed behaviours related to reporting of neutropenic sepsis.

Grounded theory enhanced ethnography because the focus was on understanding social processes, interaction and meaning, at a conceptual level rather than through description, whilst making clear the position of the researcher in constructing knowledge (Charmaz, 2006). Grounded theory ethnography led to focused and reduced data collection because data analysis began at the start of the research process and drove data collection. Similar data were not collected and analysed at the end of the research as with other qualitative methods. Rather, data were gathered to develop categories and data that would not add to emerging or completed categories ceased to be pursued (Charmaz and Mitchell, 2001, Charmaz, 2006, Timmermans and Tavory, 2010). Ongoing analysis and data collection lessened the chance of missing something important and enabled development of a more complete rich description, likely to be aligned with respondents' experiences. Grounded theory also made sense of ethnographic data that can feel unconnected. It enhanced researcher sensitivity to the emerging theoretical concepts and progressed ethnography towards theory development (Charmaz and Mitchell, 2001, Charmaz, 2006). Grounded theory and ethnographic methods were appropriate as reasons that patients delayed presenting to hospital with neutropenic sepsis were unknown. It was envisaged that reasons for such delays were likely to be complex and emotionally charged.

Chapter Five: Characteristics of participants and application of analytical techniques to generate findings

5.1 Introduction

Data were collected over a 15 month period between 25.11.11 and 13.2.13 from 35 participants, including women with breast cancer (n=13), their carers (n=9) and clinicians (n=13). The longitudinal element of the study included observation of interactions where clinicians explained neutropenic sepsis to patients and carers, informal interviews immediately after witnessed interactions and one in-depth interview with observed patients following their final chemotherapy treatment. A pilot patient participated in two additional interviews during the course of her chemotherapy to inform the study design. The retrospective study element consisted of in-depth interviews with patients following an admission to hospital for treatment of neutropenic sepsis, clinicians who engaged with patients about neutropenic sepsis and carers of patients who developed symptoms of this. Detail regarding participants who were recruited solely to the longitudinal or retrospective elements or both of these is provided within table 5.1. Participants were offered the conduct of in-depth interviews either face to face at home/ hospital or by telephone. In the event, the majority of interviews took place within the hospital or over the telephone for participant convenience (table 5.2).

Table 5.1. Recruitment to longitudinal and retrospective study elements.

	Longitudinal Only	**Retrospective only**	**Longitudinal and retrospective**	**Total**
Patients	5	8	-	**13**
Carers	3	6	-	**9**
Doctors		3	2	**5**
Nurses	5	1	2	**8**
Total	**13**	**18**	**4**	**35**

Table 5.2. Location of in-depth interviews

	Home	**Hospital**	**Telephone**	**Total interviews**
Patients	1 (3 interviews) Pilot patient.	4 (4 interviews)	8 (9 interviews)	**16**
Carers			6 (6 interviews)	**6**
Clinicians		9 (9 interviews)		**9**
Total	**3**	**13**	**15**	**31**

5.1.1 Reasons provided for declining to participate in the study

Two patients declined to participate in the longitudinal study element; one because she did not think she would gain anything from the interactions and the second because she did not want to stay for informal interviews following chemotherapy appointments. A further patient was willing to participate in the longitudinal element but was introduced to the researcher on the day of her chemotherapy consent appointment, so informed consent could not be obtained in advance. One patient and two carers did not provide reasons for declining to participate in an in-depth interview and a further two carers did not respond to the invitation passed onto them by patients. No clinicians declined to participate.

5.1.2 Sampling strategy

Four conceptual categories to explain the theory about why patients delay presenting to hospital with symptoms of neutropenic sepsis were developed through constant comparison and theoretical sampling which are core to grounded theory. Hypotheses about emerging findings were developed through constant comparison which involved comparing everything everywhere including participants' accounts, stories, actions and responses (Charmaz and Mitchell, 2000). Theoretical sampling is evident within table 5.3 which details a flexible, co-ordinated but not sequential process to recruit participants over a period of 15 months.

Table 5.3. Theoretical sampling

Observations and Interviews	Nov-11	Dec-11	Jan-12	Feb-12	Mar-12	Apr-12	May-12	Jun-12	Jul-12	Aug-12	Sep-12	Oct-12	Nov-12	Dec-12	Feb-13	Apr-13
Sophia	Ox2	I	I			I										
Sophia's Husband				I												
Doctor 1 (ONC)	O							I								
CNS 1 (BCN)	O			I												
CNS 2 (CTN)	O						I									
Adanna								O								I
Adanna's Friend								O								
Doctor 2 (ONC)								O								
CNS 4 (BCN)								O								
Melanie								O	O				I			
Melanie's Friend									O							
Doctor 1 (ONC)								O								
CNS 5 (BCN)								O								
CNS 6 (CTN)									O							
Melanie's husband														I		
Jackie									Ox2				I			
Jackie's Friend									Ox2							
Doctor 1 (ONC)									O							
CNS 5 (BCN)									O							
CNS7 (CTN)									O							
Hannah										O	I				I	
Doctor 2 (ONC)										O				I		
Lynda			I													
Lynda's Mother				I												
Paula				I												
Sam				I												
Helen					I											
Zeena					I											
Zeena's Niece								I								
Wendy								I								
Fayola										I						
Fayola's Husband											I					
Alice													I			
Alice's Friend													I			
Doctor 3 (on call)										I						
Doctor 4 (on call)												I				
Doctor 5 (A&E)													I			
CNS 3 (CTN)								I								
CNS 8 (A&E)													I			

🟦 Patient participant
🟥 Clinician participant
🟩 Carer participant
O Observation
I Interview

ONC (Oncologist)
BCN (Breast Care Nurse)
CTN (Chemotherapy Nurse)

Data were collected only from participants and at times when they were of interest to the developing theoretical categories. Furthermore, gaps in data collection illustrate breaks taken to reflect on the emerging theory and new areas of inquiry to pursue in order to develop this further. Theoretical sampling represents a different approach to other qualitative methods where data is collected prior to analysis. Application of theoretical sampling to this study ensured data collection ceased when new information did not add to the theory, rather than burdening participants through unnecessary data collection.

5.2 Patient and carer summary

A contextual summary for each patient and carer is provided in table 5.4. The aim is to illuminate demographics and characteristics of each participant and a synopsis of stories related to delayed presentation to hospital with neutropenic sepsis. Pseudonyms are used throughout.

5.2.1 Patient participants (Including the pilot patient)

Pilot data gathered from Sophia informed the design of the longitudinal element. Sophia was observed being provided with information about neutropenic sepsis by a doctor during a chemotherapy consent appointment and during a separate information session with a chemotherapy nurse. She also participated in three in-depth interviews over a five month period: on day seven of her first chemotherapy treatment, at the midpoint of chemotherapy and following completion of this. Pilot work demonstrated the benefits of non-participant observation. A close relationship that developed with Sophia over a five month period enabled in depth exploration of her thoughts and feelings related to her preparation to recognise and report signs and symptoms of neutropenic sepsis. This was later explored in relation to her accounts of willingness or ability to do so. Importantly, there were also opportunities to reflect and follow up on topics of interest identified during observations through subsequent interviews with Sophia’s husband and clinicians involved in her care.

Table 5.4. Contextual summary of patient and carer participants

Patient	**Contextual summary**
PILOT PATIENT Pt 1. Sophia C1. Husband Observation and interviews	Sophia was 64 years old and lived with her husband. They both worked within healthcare, were highly educated, analytical and self reflective and had two adult children who lived away from home. Sophia was recruited as a pilot patient and her husband was also interviewed. Sophia was followed most closely and unlike other patient participants knew the study focus was neutropenic sepsis. Sophia was independent and devastated when instructed by a breast nurse to stop working during chemotherapy. She attended chemotherapy consultations alone and lived under the shadow of possible metastatic disease from the start of chemotherapy. Bone secondaries and thus a likely reduced life expectancy were confirmed midway through treatment. Sophia knew what neutropenic sepsis was before starting chemotherapy, but she delayed presenting to hospital with infections on two occasions. On the first occasion she waited to attend a routine clinic appointment. On the second occasion Sophia was abroad with her husband who purchased antibiotics from a chemist. They delayed calling and ignored advice from the helpline to attend a local hospital and instead caught a plane home.
Pt 2. Lynda C2. Mother Interview following neutropenic sepsis admission	Lynda was a 44 year old independent professional who received adjuvant chemotherapy and attended chemotherapy information sessions alone. She took responsibility for and held the knowledge about her treatment. Lynda did not want to be seen as a sick person and lived with her male partner who was not involved with her treatment. Lynda's mother was interviewed and travelled a long distance from her home to provide practical help after each of Lynda's chemotherapy treatments. Lynda was protective of her mother who was distressed by her daughter's diagnosis. Lynda developed neutropenic sepsis and delayed presenting to hospital for several hours, claiming not to initially recognise her symptoms as important. Lynda considered hospital care during her admission with neutropenic sepsis was poor because she believed the clinicians concerned lacked the necessary expertise.
Pt 3. Paula Interview following neutropenic sepsis admission	Paula was a 52 year old hospital clerical worker. She had an active social life and lived between her home and her partner's home. Paula had metastatic breast cancer and did not perceive she had a good relationship with the oncology team. Paula was given bad news about her diagnosis and was provided with information about neutropenic sepsis at the same appointment. She delayed presenting to hospital with severe mucositis and developed neutropenic sepsis the day following her admission to hospital. On another occasion she delayed presenting with diarrhoea. On both occasions Paula initially attended her General Practitioner (GP).

(Table 5.4. continued)

Patient	**Contextual summary**
Pt 4. Sam Interview following neutropenic sepsis admission	Sam was a 45 year old woman who received adjuvant chemotherapy for breast cancer. She lived with her husband and children aged 3, 8 and 11 years. Sam, like Lynda took responsibility for and held the knowledge about her treatment and her husband was not involved in her chemotherapy treatment. Sam called the helpline when she developed generalised pain due to Docetaxel chemotherapy and felt she was made to feel a "bother". Sam subsequently did not call when she developed a sore throat and felt significantly unwell. A doctor at the next hospital visit made Sam feel she could call the hotline. She consequently called when she developed neutropenic sepsis following her second Docetaxel treatment. Sam delayed attending the hospital because she waited for her husband to get home from work to look after the children.
Pt 5. Helen Interview following neutropenic sepsis admission	Helen was a 62 year old retired woman who received chemotherapy for metastatic breast cancer. Helen lived with her husband and her daughter lived nearby. Helen developed early chemotherapy side effects, called the helpline and was advised to go to her local hospital. Helen felt a nuisance for bothering A&E staff (about non-serious chemotherapy side effects) and was sent home. As Helen became more unwell due to neutropenic sepsis she did not call the hotline, rather her daughter called Helen's GP when Helen became seriously ill. Helen's experience of her treatment for chemotherapy side effects caused her to lose confidence in the clinical team, so she decided to stop chemotherapy.
Pt 6. Zeena C6. Niece Interview following neutropenic sepsis admission	Zeena was a 61 year old widow from Somalia who was undergoing adjuvant chemotherapy. She lived with her two adult sons whom she appeared to exclude from her treatment. Zeena's niece was also interviewed, who was single and lived near to Zeena with her one year old child. Zeena's niece was the key person to support her during chemotherapy and they held the knowledge about chemotherapy rather than Zeena's sons. Zeena felt unwell for several days before being persuaded by her niece rather than her sons to call the helpline. Zeena and her niece spoke positively about their experience of calling the chemotherapy helpline and care they received within the A&E department.

(Table 5.4. continued)

Patient	Contextual summary
P7. Wendy Interview following neutropenic sepsis admission	Wendy was 61 years old, lived alone and did not work. She was undergoing adjuvant chemotherapy for breast cancer and her key source of support was her sister, who travelled a long distance from her home in Scotland to provide practical help following each chemotherapy treatment. Wendy had another sister who was dying from breast cancer. Wendy did not present to hospital when she became unwell with symptoms of neutropenic sepsis following chemotherapy. On a subsequent occasion when Wendy developed neutropenic sepsis she was persuaded to contact the hospital by her sister. Wendy waited to call a breast nurse whom she knew rather than calling the hotline number.
P8. Adanna Observation and interviews	Adanna was 56 years old, married and attended chemotherapy information sessions with her friend. She had a strong religious faith and did not believe she would develop an infection. She regularly travelled between the UK and Africa and was reluctant to stop doing this during chemotherapy. Adanna was not someone who sought out information about chemotherapy and preferred such information to be provided in a straightforward fashion. It apparently, did not upset her when the doctor told her that infections can be fatal and she may not get the right care if she developed an infection in Africa. She took the doctor's advice seriously and did not travel. Adanna did not develop an infection during chemotherapy. When she developed other chemotherapy side effects she called her breast care nurse, rather than the helpline.
P9. Melanie C9a Friend C9B Husband Observation and interviews	Melanie was a 56 year old confident company director, for whom working during chemotherapy was important for a sense of normality. Melanie attended the chemotherapy consent appointment alone and was accompanied by her friend for moral support for the first nurse-led chemotherapy treatment and information session with a nurse. Melanie described herself as a detailed person who sought and checked out information until she believed she had all she needed. Melanie said she followed instructions, but explained she delayed presenting to hospital with two infections because she did not recognise her symptoms as important and did not believe clinicians could help her. Melanie's husband was also interviewed and she described him as the diametric opposite to her. He said he did not do his own research, relied on Melanie to give him important information and was unable to persuade her to contact the hospital when she became unwell with symptoms that may have indicated neutropenic sepsis.

(Table 5.4. continued)

Patient	**Contextual summary**
P10. Jackie C10. Friend Observation and interviews	Jackie was a 53 year old divorced personal assistant who lived alone but near to her sister. Jackie and her sister had recently suffered a bereavement and were both devastated by her cancer diagnosis. Jackie had a wide circle of friends who accompanied her to chemotherapy information sessions for moral support. Jackie's sister did not attend and was unable to persuade Jackie to call the helpline when she developed debilitating diarrhoea. Jackie was reluctant to keep calling the helpline because she felt she was becoming a bother.
P11. Fayola C11. Husband Interview following neutropenic sepsis admission	Fayola was a 31 year old care home assistant who lived with her husband and two year old child. Fayola was in control of her chemotherapy treatment and made final decisions regarding this. She underwent adjuvant chemotherapy and delayed presenting for several days when she developed neutropenic sepsis because she and her husband did not perceive her symptoms to be important. An indication that Fayola did not take neutropenic sepsis seriously was further evident when she eventually called the helpline from work. She was advised to go to hospital, but finished her shift in a nursing home first.
P12. Hannah Observation and interviews	Hannah was a 74 year old retired nurse. She had experience of friends who benefited from chemotherapy but a friend and a brother had also died from cancer. She had a wide circle of friends but lived alone and appeared isolated. She had suffered with depression for many years and appeared low during interviews. Hannah said her friends worried she would not report chemotherapy symptoms because her inclination was to ignore serious symptoms, as she had done when she previously had a transient ischemic attack and when she found a breast lump, which she strongly suspected was cancer and turned out to be so. Hannah did not think she would be ill during chemotherapy and aligned herself with apparently well patients undergoing chemotherapy. She did not call when she developed a fever and diarrhoea following her first chemotherapy treatment. She did present without delay on a second occasion because a doctor she had a good relationship with had reinforced the importance of doing so.

(Table 5.4. continued)

Patient	**Contextual summary**
P13. Alice 61 years C13 Friend Interview following neutropenic sepsis admission	Alice was a 61 year old therapist who lived alone. During an appointment with a doctor Alice was told she had metastatic breast cancer, provided with information about chemotherapy side effects and signed the chemotherapy consent form. Alice was an intelligent, independent woman who appeared anxious and talked a lot. She was devastated by her diagnosis, wanted all the information and took friends to chemotherapy information sessions to note this down as well as for moral support. Alice's friend lived a long distance away and came to her chemotherapy information sessions. Alice followed instructions implicitly but delayed reporting symptoms of neutropenic sepsis, explaining she did not recognise these as significant. Her friend who had accompanied Alice to chemotherapy information appointments was able to persuade her to call the helpline. Alice was advised to go to A&E but was sent home despite having a low white count. Alice was subsequently asked to return to hospital by an oncology doctor, but refused stating this was because they had a poor relationship and she wanted to enjoy a planned day out.

Pilot work informed revisions of the research protocol which was taken back to the ethics committee as a minor amendment (appendix 2). Revisions included addition of digital audio-recording of observed chemotherapy consultations between clinicians and patients, to improve recall and concentration on witnessed interactions. Sophia was aware at the outset the research focus was on neutropenic sepsis, which in retrospect might have altered her perception and behaviour. Subsequent patients were consequently informed the study intent was to explore their experience of chemotherapy side effects. They were informed only at the end of treatment interview that the study focus was on neutropenic sepsis. The pilot further identified one interview at the end rather than three throughout treatment would reduce patient burden. The first interview, carried out at day seven of chemotherapy, was removed from the protocol. This was because captured data about the pilot patient's experiences and views of information and support provided about neutropenic sepsis could have been gathered within the observation period.

The second interview scheduled for mid treatment was also removed from the study protocol because Sophia's experience of two infections she developed during chemotherapy could have been captured within her final interview. Consequently, four subsequent patients who were recruited to the longitudinal element were not interviewed on day seven or at the mid treatment point. Rather, they were recruited to participate in non-participant observation of chemotherapy information appointments conducted separately with a doctor and a chemotherapy nurse and one end of treatment in-depth interview. Scheduling conflicts due to the researcher being on annual leave resulted in missed opportunities to observe Adanna and Hannah's information sessions with a chemotherapy nurse. An additional interview was carried out with Hannah shortly after the unobserved appointment which captured her experience of initial information and support provided by chemotherapy nurses. This was not possible for Adanna who did not respond to attempts to contact her by telephone.

During the third month of pilot data collection following non-participant observation and interviews with Sophia, her husband and the clinicians providing her care, initial concepts began to emerge to pursue with other participants. Audio recorded retrospective in-depth interviews (offered face to face at home / hospital or telephone) were then commenced with participants identified through theoretical sampling and constant comparison as important to the developing theory. In depth interviews carried out with patients (n=8) following an admission to hospital with neutropenic sepsis enabled explorations of their perceptions of information and communication about neutropenic sepsis, beliefs about this condition, admission to hospital and any delays in identification and treatment of it. Constant comparison raised hypotheses about patient characteristics that may have influenced delayed presentation. Consequently, a range of patients were recruited (table 5.5) to the longitudinal (n=4) and retrospective (n=8) elements through theoretical sampling. Patients' ages ranged from 31 to 74 years and ethnicity was mixed; for five patients English was not their first language. Five out of thirteen patients lived alone and one did not have an identified carer. There was an imbalance in educational status as nine patients held degree level qualifications or above. Disease status became of interest during the research. However, clinicians appeared to find it more difficult to identify patients for the study who had metastatic or incurable (n=4) than potentially curable (n=9) cancers.

Table 5.5. Patient demographics (n=13)

	Number of patients
Age	
30-39	1
40-49	2
50-59	4
60-69	5
>69	1
Regimen	
FEC (5-Fluorouracil, Epirubicin, Cyclophosphamide) and a Taxane	4
FEC (5-Fluorouracil, Epirubicin, Cyclophosphamide) OR EC Epirubicin, Cyclophosphamide)	5
Docetaxel	3
Docetaxel & Cyclophosphamide	1
Treatment Intention	
Palliative	4
Adjuvant	9
Living Arrangements	
Alone	5
Husband/partner	7
Identified carer	10
Adult children	1
Ethnic Group	
White	8
Black British	1
Black African	2
African Asian	1
Seychelles	1

(Table 5.5. continued)

	Number of patients
Education	
Secondary School	4
College degree	1
University degree	5
Post graduate degree	3
Occupational group	
Unskilled never worked	2
Skilled	4
Managerial	1
Professional	6
Employment status	
Never worked	2
Not working due to ill health	5
Retired	2
Working part time	1
Working full time	3
Dependents	
Child under 18	2
Elderly or sick relative	0

5.2.2 Carer participants

Carers (n=9) were recruited through patients. Three carers participated in the observation element and six each took part in an audio recorded in-depth interview. Accounts of carers of patients who had been admitted to hospital with neutropenic sepsis or who had developed infections were pursued as these appeared most significant to the developing theory. Theoretical sampling resulted in a range of carer characteristics (table 5.6). A range of relationships were also represented and 50% of carers lived with patients. Some carers were recruited because patients identified them during interviews as assisting in the identification and reporting of neutropenic sepsis symptoms and others because they did not appear as involved. Carers were highly educated and all held qualifications of degree level or above.

Table 5.6. Carers demographics interviews (n=6)

	Number of carers
Relationship to patient	
Husband	3
Mother	1
Niece	1
Friend	1
Living with patient	
Yes	3
No	3
Ethnic group	
White	2
European	1
Black African	1
African Asian	1
Italian	1
Education	
Secondary School	0
College degree	0
University degree	3
Post graduate degree	3

(Table 5.6. continued)

	Number of Carers
Occupational group	
Unskilled never worked	0
Skilled	0
Managerial	2
Professional	4
Employment status	
Never worked	0
Not working due to ill health	0
Retired	1
Working Part time	1
Working Full time	3
Student	1
Dependents	
Child under 18	3
Elderly or sick relative	0

5.2.3 Clinician participants

Thirteen clinicians were recruited, four of whom took part in observation and in-depth interviews, a further four took part in the observation element only and five participated in an in-depth interview only. Demographical details provided in table 5.7 demonstrate that the majority of doctors were male and the majority of nurses were female.

Table 5.7. Clinician demographics (n=13)

	Sex	Role	Observed Consent Appointment	Observed Chemotherapy Nurse Appointment	Interview
Doctor 1	F	Consultant Medical Oncologist	√		√
Doctor 2	M	Consultant Medical Oncologist	√		√
Doctor 3	M	Clinical Fellow in Medical Oncology			√
Doctor 4	M	SPR			√
Doctor 5	M	A&E Consultant			√
CNS1	F	Breast Care Nurse	√		√
CNS2	M	Chemotherapy Nurse		√	√
CNS3	F	Chemotherapy Nurse			√
CNS4	F	Breast Care Nurse	√		
CNS5	F	Breast Care Nurse	√		
CNS6	F	Chemotherapy Nurse		√	
CNS7	F	Chemotherapy Nurse		√	
CNS8	F	A&E Nurse			√
Total			**5**	**3**	**9**

Initially, the recruitment of clinicians were confined to members of the breast cancer team including chemotherapy nurses, breast care nurses and oncology doctors who provided information about neutropenic sepsis to patients. Theoretical sampling next led to the recruitment of clinicians who managed the on call service or who worked within the A&E department.

Two doctors who manned the chemotherapy helpline were recruited because early analysis suggested patients did not want to use the service. Furthermore, observed doctors (unlike chemotherapy nurses) were not directly involved in providing this service. Analytical questioning developed through memo writing directed exploration of perspectives of these doctors about dealing with patient calls. These included types of conversations held with patients about neutropenic sepsis and any competing pressures or frustrations. A nurse and a doctor who worked within the A&E department were also recruited. This was because patients, carers and oncology clinicians indicated patient' experiences of being treated for chemotherapy side effects within A&E departments impacted on their willingness to attend again. Areas of enquiry that emerged as important during analysis that were explored with the two recruited A&E clinicians included experiences of: communicating with the oncology team; patients' awareness of neutropenic sepsis and any thoughts about why they might delay.

5.3 Application of analytical techniques

5.3.1 A worked example

The grounded theory approach enabled development of four conceptual categories made up of 11 properties. These evolved and were reconstructed to develop a theory grounded in the data. This describes why patients delay presenting to hospital with symptoms of neutropenic sepsis. Categories include: "*Playing down the seriousness and piling on the fear*" (Core category); *"Getting away with It"; "Making the connection"* and *"Relationships core to accessing help"*.

Categories were developed and collapsed to represent the emerging theory. For example the categories *"Relationships facilitate adherence"* and *"Accessing help"* were combined to the more conceptual category *"Relationships core to accessing help."* Properties that conceptually described the same phenomena were also collapsed and the most pertinent title chosen. Categories and properties that became irrelevant to the theory including *"chemotherapy brain"* were discarded. A summary of coding phases is presented in table 5.8 and examples of coding within NVIVO software (Version 9) are included within appendix 6.

Table 5.8. Coding phases: summary

Coding phases	Dates	Data sources	Codes	Categories
Phase 1 initial Coding	26.3.12 - 30.5.12	First 10	80 (allocated to PCC domains)	-
Phase 2 initial coding	30.5.12 - 13.7.12	First 22	156 (allocated to PCC domains)	-
Phase 3 (focused coding)	13.7.12 - 13.8.12	First 22	41	6 early categories
Phase 4 (focused coding)	13.8.12 – 4.10.12	First 22	22	6 focused categories
Phase 5 (category development)	4.10.12- 19.9.13	39	11 properties	4 final focused categories

5.3.2 Developing the core category

A worked example focuses on the development of the core category (Playing down the seriousness and piling on the fear). Coding phases (table 5.9) included initial coding. This involved staying close to the data to identify 32 descriptive codes that formed the early category. Initial descriptive codes were transcribed onto strips of paper and those that appeared conceptually similar were clustered together (see figure 4.2., p101). This process resulted in the category provisionally being labelled *"Conveying the seriousness".* Properties were further refined by collapsing / joining together initial codes that essentially described the same process. For example the following initial codes were grouped or collapsed under the more conceptual property, "*Playing down the seriousness, skirting round the issue."*:

"Playing down the seriousness, skirting round the issue;" "Saving face avoiding criticism;" "Seeking to reassure;" "Focusing on infections"; "Backed into a corner", "Resenting chemotherapy"; "Giving the worst case scenario" and *"Not engaging in conversations about serious side effects".*

The early category was made up of six properties. Further focused coding narrowed properties to four and developed the more abstract and conceptual category title, *"Playing down the* *seriousness piling on the fear*." Conceptual development of the category is further evident through collapsing the properties "*Fearing dying"* and *"Requiring chemotherapy brings home the seriousness of my situation - being hit by the gravity"* to develop a final property entitled *"Reality hitting."*

Focused coding was assisted by systematic comparison, memo writing and diagrams employed to build the category and to explore dimensions within this. As data were collected the language used by participants, emotions expressed metaphors and similes and negative cases were explored and particular attention paid to anything puzzling and red flags which indicated areas for further enquiry. Sensitising concepts were used to ask questions of the data, to look for what was behind the text, to move the theory along. Reflective thought included asking what seemed to be going on, and what struck as significant about it. This process is demonstrated through building up an interconnected picture of thoughts, beliefs, actions and consequences in relation to conveying the seriousness of neutropenic sepsis.

Analytical thinking behind the development of the core explanatory category; *"Playing down the seriousness and piling on the fear"* and the four properties within it is next described. More detailed memo exerts and analytical diagrams are included within appendices 8 and 9.

Table 5.9. Coding phases to develop the core category

Phase two. Initial coding (32)	Phase three. Focused coding (6). Category: Conveying the seriousness	Phases four and five Focused coding (4). Playing down the seriousness, piling on the fear
Uncertain if patients will call	**Property one.** Clinicians worrying/frustrated	**Property one.** Holding in the frustration
Frustrating for clinicians		
Worried clinicians		
Playing down the seriousness, skirting round the issue	**Property two.** Playing down the seriousness, skirting round the issue	**Property two.** Playing down the seriousness
Backed into a corner resenting chemotherapy		
Seeking to reassure		
Providing prophylaxis		
Not engaging in conversations about serious side effects		
Giving the worst case scenario		
Saving Face avoiding criticism		
Focusing on infection		
Recognising and informing riskier patients	**Property three.** Informing riskier patients	**Property three.** Piling on the fear
Being honest about side effects		
Personalising my information		
Drumming it into me, it’s their job		
Instructing and obeying the rules		
Making me accept the risk		
Drip feeding timing of information		
Scary information		
No time to take it in		
Standard repertoire – going through the motions	**Property four.** Standard repertoire. Going through the motions	
Personalising my information		
Checking understanding		
Having enough time for me		
Developing a rapport		
Explaining my personal risk		

(Table 5.9. continued)

Phase two Initial coding (32)	Phase three. Focused coding (6). Conveying the seriousness	Phase four and five. Focused coding (3) Playing down the seriousness, piling on the fear
Information overload overwhelming	**Property five.** Requiring chemotherapy brings home the seriousness of my situation: Being hit by the gravity	**Property four.** Reality hitting
Being hit by the gravity of the situation		
Chemotherapy conversations heighten anxiety		
Dealing with cancer uncertainty	**Property six.** Fearing dying	
Dealing with other bereavements		
Fearing I might die		

5.3.2.1 Property one: Holding in the frustration

Initial enquiry with clinicians focused on their experiences of patients who delayed presenting to hospital with neutropenic sepsis and beliefs about why such delays occurred. Clinicians expressed frustrations associated with this, and these appeared important so were explored further to identify why these happened and the impact of these on communication with patient and carers about neutropenic sepsis (See Property two: Playing down the seriousness and Property three: piling on the fear).

5.3.2.2 Property two: Playing down the seriousness

Conflicting or negative accounts that appeared to challenge the emerging theory were compared. For example, clinicians believed they explained the risks and symptoms of neutropenic sepsis to patients but some patients and carers denied knowledge of this. Constant comparison between clinicians' accounts of their feelings and observation of their practice in relation to explaining neutropenic sepsis to patients underpinned the property, *"Playing down the seriousness."* This was also informed by patient' and carer' accounts of their reactions to hearing about neutropenic sepsis and written explanations of it. A discomfort was identified in that clinicians avoided fully explaining neutropenic sepsis to patients who often also did not want to hear about it.

The flip flop technique, described by Corbin and Strauss (2008) involved thinking about a concept and what the opposite perspective might be, in order to generate new questions to ask of the data. Consequently, thought was given to what it might be like for patients and carers to be explicitly told about the risk of death from neutropenic sepsis. Discussions with subsequent patients and carers explored their understanding of neutropenic sepsis and the risk of death. They were also asked how they would have felt about being given this information before starting chemotherapy. Questioning of clinicians and the data further focused on gaining a greater understanding of clinicians' feelings and attitudes about talking with patients about the risk of death from neutropenic sepsis and occasions where this was more or less explicitly explained and why.

5.3.2.3 Property three: Piling on the fear

Observation of the tone and language used by clinicians to explain neutropenic sepsis to patients identified that this explanation did not appear personalised and lacked emotion. The need to attend hospital if unwell was also often repeatedly stressed. Clinicians were asked about their relationships with patients and carers and how they coped with providing the same information about chemotherapy side effects to multiple patients. This was to identify any connections between this and their frustrations (See Property one: Holding in the frustration) and apparent unwillingness to speak about neutropenic sepsis with patients (See Property two: Playing down the seriousness).

Focused questioning with patients and carers explored perceptions about their relationships with clinicians, their experience of information provided about neutropenic sepsis and their reactions to it. Most patients feared and did not want to hear about neutropenic sepsis. Properties in grounded theory are extended or developed through seeking out disconfirming cases. A conflicting account enabled greater understanding of fear that affected patients' ability to hear about neutropenic sepsis. Melanie, unlike other patients, understood neutropenic sepsis and was not fearful of it. However, she appeared unable to hear about it when also taking in unexpected bad news about her cancer prognosis.

5.3.2.4 Property four: Reality hitting

During observed consultations with clinicians, patients appeared to become progressively anxious as chemotherapy side effects were explained. In order to better understand this, patients and carers were asked about pre-existing emotions. It emerged fears related to having a life-threatening illness and starting chemotherapy were important to engaging with information about neutropenic sepsis. This led to close observation of the language used by clinicians (See Property three: Piling on the fear) and focused exploration with patients and carers about why this information made them feel anxious. As this property developed, it became clear that information about neutropenic sepsis heightened fears and further attention was paid to how different patients and carers were affected by and reacted to this information.

The four properties were brought together as different facets to develop the overall category of "*Playing down the seriousness and piling on the fear*." This conceptually defined a process where clinicians who were frustrated by patient delays in reporting neutropenic sepsis and uncomfortable about talking about the risk of death attempted to convey the risks of neutropenic sepsis by frightening patients but not explaining why this could be dangerous.

Chapter summary:

Data were generated over a period of 15 months from 35 participants who included women with breast cancer undergoing chemotherapy (n=13), their carers (n=9) and clinicians, comprising of nurses (n=8) and doctors (n=5). The longitudinal element was refined through recruitment of a pilot patient. For subsequent patients this involved observations of two appointments where neutropenic sepsis was explained to patients and carers by clinicians and informal interviews about witnessed events. One in-depth interview was further conducted with patients following their final chemotherapy treatment. The retrospective element comprised of in-depth interviews with patients with experience of neutropenic sepsis, carers and clinicians.

Four categories and 11 properties emerged from the data. This was achieved through identification of initial descriptive codes which were developed through focused coding to a conceptual level. This process was assisted by analytical techniques core to grounded theory, including constant comparison and theoretical sampling. Constant comparison involved becoming immersed in the data and alternating between this and new participants to compare everything everywhere. The process was aided by analytical memos and diagrams to generate hypotheses. These were developed or discounted through theoretical sampling of participants thought to be of interest to the emerging theory. Participants who were recruited included patients commencing chemotherapy, those who had developed neutropenic sepsis and carers of patients who had developed symptoms of it. Patients and carers held a range of characteristics and relationships. They tended to be highly educated and it was difficult to recruit patients who had metastatic disease. Clinicians who participated in the study included nurses and doctors who worked within oncology and A&E settings. Importantly the co-ordinated but not sequential research process meant participants were not burdened with unnecessary data collection as this ceased as categories became developed.

Chapter Six: Findings

6.1 Findings

Findings demonstrated that 12 of 13 patients, who participated in this study, delayed contacting clinicians when they developed symptoms suggestive of neutropenic sepsis (table 6.1). Seven patients delayed presenting with symptoms of infections (not confirmed as neutropenic sepsis) on eight occasions. Two of these patients called the helpline, one waited for a routine appointment and two patients waited to contact their GP to report their symptoms. Three patients did not contact a clinician about symptoms indicative of neutropenic sepsis. All eight patients who were diagnosed with neutropenic sepsis also delayed presenting to hospital. They included three of the previously mentioned patients, two of whom had not earlier contacted clinicians about their symptoms and one who had sought advice from her GP. Of the eight patients who developed neutropenic sepsis, five presented through calling the helpline and one waited to contact the breast care team. A further two patients reported their symptoms to GPs.

Table 6.1. Data related to delayed presentation

	Developed symptoms suggestive of neutropenic sepsis (Not confirmed as neutropenic sepsis)	**Confirmed neutropenic sepsis**
Called the hotline	Jackie, Sophia	Sam, Fayola, Zeena, Alice, Linda
Did not contact a clinician	Hannah, Wendy, Sam	0
Waited to contact the breast team	Sophia	Wendy
Waited to contact the GP	Melanie, Paula	Paula, Helen
Deaths	0	0
Total Delays	**8 (7 patients)**	**8 (8 patients)**

Four categories made up of eleven properties (table 6.2) emerged to describe why patients may delay presenting to hospital when they develop neutropenic sepsis.

Table 6.2. Categories and properties

Core category:	**Playing down the seriousness and piling on the fear**
Property one:	Holding in the frustration
Property two:	Playing down the seriousness
Property three:	Piling on the fear
Property four:	Reality hitting
Category two:	**Getting away with it, wanting normality and control**
Property one:	Ignoring the risk
Property two:	Feeling protected from infection
Property three:	Getting away with it
Category three:	**Making the connection**
Property one:	Not hitting my radar
Property two:	Getting a wakeup call
Category four:	**Relationships core to accessing help**
Property one:	Bothering the helpline
Property two:	Carers an untapped resource

6.1.1 Core category: Playing down the seriousness and piling on the fear

Clinicians felt frustrated that patients delayed presenting to hospital with neutropenic sepsis because they knew this heightened the risk of serious illness or death. They conveyed their frustration to patients by repeatedly stressing the need to call with a fever, whilst trying to save face and avoid criticism by minimising neutropenic sepsis to an infection in attempts to avoid instilling fear. Clinicians only explained that infections during chemotherapy could kill as a ‘scare tactic’ to patients considered being at risk of not reporting neutropenic sepsis. Importantly, starting chemotherapy heightened patients’ fears of dying which were further exacerbated through clinicians piling on the fear about neutropenic sepsis. In addition, patients who had recently experienced a close bereavement (death of a close friend or family member) or who had metastatic disease appeared most fearful of neutropenic sepsis. This may have been due to pessimism about surviving cancer.

6.1.1.1 Property one: Holding in the frustration

Clinicians had experience of patients who had quickly become seriously ill due to neutropenic sepsis. This was alarming, as described by doctor 3:

"…there was one youngster…he had just finished his high dose chemo…we saw him on the ward round and he was sat up sweating, looked terrible, trying to force a smile because he wanted to go home and then we walked away and within about 15 minutes a crash call went out, his blood pressure had dropped, he was overtly septic"

(Doctor 3)

Consequently, neutropenic sepsis was a high profile condition amongst clinicians and an educational priority for junior doctors as explained again by Doctor 3: *"…we're taught about manning the chemotherapy hotline we're made aware that that's one of the big things we have to look out for...we know that's very dangerous…"* Clinicians also referred to patients delaying seeking medical help when they developed neutropenic sepsis. This was the case for all patients from this study who developed infections (n=12). Delays were a source of frustration for clinicians, especially when patients came close to death or died. Doctor 2 spoke about:

"…a patient who became severely ill at home and went to bed for a couple of days before she got admitted through casualty straight to ITU and jolly nearly died… is only just up and about now over a year later and of course never got all her planned adjuvant treatment either chemotherapy or radiotherapy... why did she stay at home for two days semi-conscious, her family calling into her but nobody actually contacting us, I don't know... it is devastating. I've had one death…very knowledgeable patient but she sat at home presented too late and once you get established gram negative septicaemia as opposed to just the bacteremia then it is very hard to reverse the consequences".

(Doctor 2)

Clinicians were eager to avoid this happening to other patients and as Doctor 2 pointed out wanted them to: "…*know what to do to be safe."* Doctor 3 reiterated: "…*from my own experience… how things can go so bad so quickly and that ultimately it's better to prevent that from ever happening".* Clinicians used words like *"frustrating" "disappointing" "pissed off" "annoyed"* and "*cross"* to describe their feelings about patient delays and blamed patients for not taking responsibility for this chemotherapy complication. Doctor 2 said patients: "…*have* *got to be prepared to participate in their care"* and Doctor 1 said: *"…it's sort of their foolishness… it can potentially be so dangerous …you've tried to give good advice that's then just completely ignored…it's quite frustrating…"* Some clinicians reprimanded patients when they did not adhere to instructions (See Property three: Piling on the fear), but others referred to holding in the frustration as described by Doctor 3: *"…you can't get angry…we're like well done for checking again, can you get to [name of ward] right now, as soon as possible".*

6.1.1.2 Property two: Playing down the seriousness

Clinicians appeared to be frustrated by patients' delayed presentation to hospital with neutropenic sepsis. However, they also apparently minimised neutropenic sepsis to an infection and did not inform patients this could rapidly lead to secondary complications of sepsis, organ failure and death. Words including neutropenic sepsis, septicaemia, blood poisoning or blood infection were never used by clinicians when informing patients about risks of infections and did not appear in written patient chemotherapy information. The words *"Neutropenic Sepsis"* and *"Emergency"* were only included within written information provided to patients to show clinicians (e.g., GP's or those working within A&E departments) should they become unwell during chemotherapy, including a chemotherapy alert card (figure 6.1).

Figure 6.1. Chemotherapy alert card

IMPORTANT: A&E STAFF AND PRIMARY CARE

This patient is at risk of neutropenic sepsis, which is a MEDICAL EMERGENCY

REFER TO YOUR LOCAL ACUTE TRUST NEUTROPENIC SEPSIS POLICY IMMEDIATELY

Inform patient's consultant within 24 hours

Card produced by Pierre Fabre Oncology

Pierre Fabre

CHEMOTHERAPY ALERT CARD

Name ……………………………………………
Hospital number ……………………………………
Consultant ……………………………………… at
………………………………………………… Trust
Chemotherapy
Regimen ………………………………………………
CHEMO UNIT tel. no …………………………………
OUT OF HOURS tel. no ………………………………

Observed clinicians generally used emotive words like "*it's serious*" *"we worry"* "*you need to call us quickly"* when hinting at serious infections and the importance of reporting fevers (See Category three: Making the connection), rather than explaining the risk of death from sepsis. Lynda said: *"…*[name of hospital] *had done a very good job of drumming it into me that eh if I notice anything like a temperature then to call it straight away and don't delay".* Doctor 1 was observed advising Sophia *"…don't just think prrrr it's a bit of a cold, I'll be fine because* *ordinarily of course you would be, but on chemotherapy you may not be, so if you get a temperature, you let us know".* and CNS 6 told Melanie: *"The most important thing out of all the side effects… is the temperature, because that's the one big thing, infection is one big thing".* Written chemotherapy information provided to patients also focused on infections and the importance of reporting a fever rather than sepsis as demonstrated within the following example:

Risk of infection: *FEC can reduce the number of white cells in your blood, which help fight infection. White blood cells are produced by the bone marrow. If the number of your white cells is low you'll be more prone to infections. A low white cell count is called neutropenia… Contact your Doctor or the hospital straight away if:Your temperature goes above 38^{O}C (100.4^{O}F) You suddenly feel unwell even with a normal temperature*
(Reproduced from Macmillan Cancer Support FEC (5 fluorouracil, Epirubicin and Cyclophosphamide) information sheet (accessed 8/10/2012).

Some clinicians indicated they believed this approach got the message across to patients that infections during chemotherapy could be serious. CNS 8 said: *"…I would never be honest and say look it can kill you but I would say it's really severe this neutropenic".* CNS 2 told patients: *"…in a very subtle way that it is the number one cause of death among patients having chemotherapy"* and CNS 3 thought: *"…without even telling them that you are at risk of dying they already know."* Even when patients were informed they could die from neutropenic sepsis this remained minimised to an infection, was glossed over and not explained or discussed. Doctor 2 said: "*Occasionally this* [neutropenic sepsis] *results in very severe illness or death, which is what I try and warn them about".* This Doctor was observed to mention the risk of death to Adanna and Hannah but said he did not tell patients why: "*…infections could be fatal".* Similarly, CNS 1 was not observed to encourage discussion when she told Sophia: "*…you don't have the ability to fight infection. It's a life or death situation* (speaking quickly)*. We are talking about a temperature of 38…"*

Some clinicians appeared concerned that conveying the risk of death from neutropenic sepsis may unleash emotions they would struggle to deal with in patients already anxious about starting chemotherapy. Doctor 4 said: "*I know that not everyone stresses the fact that it could* *be fatal… and I didn't when I first became a registrar and I think it's quite a hard thing to say to people…"* and Doctor 5 said: *"…it's a difficult conversation to have".* CNS 8 said she: *"…personally didn't want to scare patients so tried to go down the nice nice route" and further explained: "…it's quite a hard thing to go about saying".* A discomfort and unfamiliarity about discussing the risk of death from neutropenic sepsis was evident within the accounts of Doctors 1, 2 and 4. Doctor 2 said: *"We don't like hurting our patients; we don't like killing them so we have difficulty admitting that this is the consequence of our action".* Doctor 1 said a new chemotherapy consent form had: *"…life threatening infection as a tick box…I guess we will…discuss it in those terms more... life-threatening is still a bit more pleasant… than saying risk of death*" and Doctor 4 also said: *"…there is an area of possibly fatal side effects* [within the chemotherapy consent form] *I think it even says…neutropenic sepsis…"*

Some clinicians' accounts further suggested an underlying concern that patients already reluctant to have chemotherapy may refuse this if they fully explained the risks including neutropenic sepsis. Most patients feared chemotherapy but felt they had no choice but to go ahead with it. Chemotherapy was described by Sophia, Jackie, Alice and Lynda's mother as *"poisonous"* by Melanie as *"toxic"* and by Jackie as *"alien".* Sophia, during her first interview said: *"…we are still using mustard gas which was used to kill people in the war* (both laugh)*…"* For some patients chemotherapy went against usual healthy principles. CNS 2 said some patients: *"… will tell you oh I don't like to take a lot of medications…"* Sophia said during her first interview: "*…I'm not into pills too much… just the idea of pure"* and Melanie: *"…didn't want it* [chemotherapy]*….As somebody who hates taking medication… whose generally very healthy…a toxic cocktail put into my veins was something that really I was not happy about…".* Other patients spoke more specifically about fears of possible organ damage. Jackie said: *"... will it affect my heart later on or my liver or my lungs..."* and Fayola said: *"… I'm young I still want to have a child …I was thinking I don't need it* [chemotherapy] and she also worried: *"… chemotherapy can cause a second cancer…"* Some patients appeared less reluctant to have chemotherapy. Zeena said: " *I'm not worried about so much about the chemo….I hope it* [the cancer] *goes away, it doesn't come back"* and Hannah had: "*…total faith that once it was all over… the cancer would be gone"* and she: "*…didn't feel scared of it* [the chemotherapy]*… I thought it's something that I'll get through and I felt that I would stand up to it pretty well* [See category two: Getting away with it]". Patients who feared damage from chemotherapy felt backed into a corner. Doctor 1 was observed advising Jackie and Melanie: "… *you can change your mind anytime…"* both of whom laughed quietly to themselves. Melanie was then observed to inform Doctor 1: "*I'm going to get this toxic cocktail, come what may"* and Jackie said: *"… I was in two minds whether to have it or not…if I don't have it there's a possibility it will come back… might be a bit more serious…I sort of decided to have it…endure the next five months of treatment… I felt I didn't really have a choice…".*

Clinicians were aware that many patients reluctantly agreed to have chemotherapy. CNS 1 believed: *"…patients think oh god as much as I don't like being on chemo, I know I need to have it…".* Some clinicians may have consequently avoided discussions with patients about possible benefits and disadvantages of chemotherapy through a concern not to encourage refusal. Doctor 5 who worked in A&E and had oncology experience said: *"…our gut instinct is that we should give them this treatment and we don't want to tell people things that mean they are going to refuse….".* This behaviour is also evident within the accounts of some oncology doctors. Doctor 2 volunteered unprompted: *"… I don't particularly worry about telling them things that might stop them having the treatment but it's just helping them manage the anxiety state that they're already in..."* Doctor 1 said: *"…people are so worried you have to spend a lot of time reassuring them, that in fact you'll get them through the treatment. It won't be that awful".* Doctor 1 also said: "*…it's the same as with cardiac damage from the anthracyclines and leukaemia, I don't tend to talk about them because they are so rare. I will if asked…it's not something you want to be telling them about you want to highlight the seriousness of it but not kind of the risk of death because that is so rare…".*

Doctors may have further particularly avoided discussions about prognosis and potential benefits and risks of chemotherapy including neutropenic sepsis with patients who had a worse prognosis. Doctor 4 said: "*There are some patients when you can see they are absolutely terrified by the whole prospect of chemotherapy and you know that chemotherapy is going to be very beneficial to them. They're the kind of patient I probably would say it's important to call us rather than telling them that* [the risk of death from neutropenic sepsis]*".* For Melanie requiring chemotherapy meant her prognosis was worse than she initially thought. Melanie was observed to ask about her prognosis during her chemotherapy consent appointment. Despite this, her husband said after she finished chemotherapy 6 months later: "*…nobody has said … people who get a secondary cancer in your condition after 5 years is X and after 10 years is Y. That's not been done and I know that she has kind of asked that once or twice...."* Melanie's husband also indicated the severity of chemotherapy side effects had been underplayed by clinicians who: *"… don't really want to give bad news. ….nobody has said* *to her look this is changing your life…you're going to go through six months of hell…I think that's about treating people as grown-ups".*

A behaviour, where clinicians appeared to avoid discussing the benefits and risks of chemotherapy with patients is also evident within the accounts of Sophia, Alice, Paula and Helen who had metastatic disease. Sophia was observed during her chemotherapy consent appointment to be most worried about the possibility of having bone secondaries. During her first interview Sophia said: *"…I just couldn't imagine that anything could make me better* and during her final interview when she knew she had metastatic disease said: *"…its [chemotherapy] such a sort of poisonous substance …I did worry…that the treatment might be worse … than having the cancer….*" Sophia also said clinicians caring for her did not like her describing chemotherapy as poison and told her: *"… you've got to stop thinking in this way ..." and* "*Everyone said oh you've got to be really positive... but I didn't think you could be that positive…you can't just say it's going to be alright because it probably might not be…".* Doctor 1 was observed to advise patients receiving adjuvant chemotherapy they could choose not to have chemotherapy. Doctor 1 did not offer Sophia the same choice and by her final interview Sophia said she: "… *still don't know what it really means* [to have bone secondaries] *except that it's stopped for the moment".*

Similarly, Paula said she started chemotherapy unaware of the risks involved: *"…because the way they were speaking…it* [chemotherapy] *would not have such a greater impact…"* and: "*…the importance of it* [infections] *just was not emphasised".* Alice had refused adjuvant chemotherapy six years previously because: "*I saw myself doing chemo and I saw it like a tree with all the leaves blown off, and not doing chemo and the tree with leaves still on but coming to the same point".* Alice's friend described an oncology Doctor instilling: "…*a sense of hope, even though we are looking at palliative care… that this treatment would have some positive effects on her whole life*" and Alice conceded: "…*I've got to this time, I didn't do it* [chemotherapy] *before…."* When Alice developed neutropenic sepsis she inferred she had been misled because: *"…they minimise the side effects so nobody was busy saying this is how it's going to be"* and*: "…they don't want people not to do chemo".* Helen also alluded to feeling misled about chemotherapy side effects and decided not to continue with this following an episode of neutropenic sepsis. Helen said: *"I wasn't told much about this illness* [neutropenic sepsis] *I didn't even know what it was… I just thought well everyone gets handed one of these cards* [chemotherapy alert card] *to carry around with them… he* [chemotherapy nurse] *says to me… you probably won't need it…"* Helen also said: "…*I had been assured before I got this chemotherapy… I was told well sickness isn't one of the side effects of this. My God, was I sick. So I decided then you know they can't cure me, and it's spread to my lungs, I decided I wasn't going to take the chance and be like that again".*

6.1.1.3 Property three: Piling on the fear

Clinicians did not want to tell patients about the risk of death from neutropenic sepsis. Most patients also held pre-existing fears about chemotherapy. Doctor 1 said patients had a: "… *huge amount of pre-conceived baggage… of how awful it's going to be..."* Alice said: *"…I was terrified of it…"* and Melanie, during an observed consultation with Doctor 1 said she felt: *"…routine panic and terror".* When asked during an informal interview what she had meant, Melanie elaborated: *"…it has a dreadful reputation…so I was like…this is going to be horrendous".* Alice's friend said: *"…there is so much fear around at that time…although it's important to understand what the risks are so that you can really act on anything very quickly it's also quite difficult to stop piling on more fear".*

The way information about neutropenic sepsis was delivered appeared to heighten patients' anxiety in part because clinicians' frustrations emerged through repeatedly stressing the need to call urgently with a fever on up to three occasions as explained by Doctor 4:

"..we see them twice when we are consenting them, we see them the very first time and I say it then and then you give them the information to read and then you see them back a week later and you say it to them again how important it is and then when they go for their first dose of chemotherapy they have a talk from one of the chemotherapy nurses upstairs and then they tell them about that as well. So really just trying to stress that as many times as possible and in fact with all the side effects [fever] *that is the one I say to the patients is the most important…*"

Clinicians delivered information about neutropenic sepsis to patients alongside complex information about a number of frightening sounding chemotherapy side-effects. This emerged as a dispassionate standard repertoire with an apparent aim of transferring responsibility for chemotherapy side effect management to patients. Doctor 4 referred to using: *"…the same sort of stock phrases…"* and CNS 3 said: *"….you just get really tired of… it's just automatic that* *you say…the side effects…"* Doctor 1 echoed this view: *"…it's almost sort of comical … you just go into kind of automatic… it's the most standard patter you have…."* This was a tick box exercise and chemotherapy consent forms and checklists were used to ensure everything had been covered as described by CNS 3 who said: *"…it's already pre-printed all you need is to just tick what you've discussed with the patient…".*

This approach to information delivery caused some patients to feel processed through a busy inflexible system which did not adjust to individual needs. Sam said: "*It's the doctors they just have to do their job…"* and she described being told: "*…Your hair <u>will</u> fall out in three weeks' time (laughs)…You know it's quite shocking…"* and Sophia elaborated: "*I realised it was a kind of, it wasn't a spiel but I realised she has to do that…but in fact it's all a bit stupefying the whole process."* Sophia's husband said: "*They haven't got time enough to adjust…to the individual…"* and Paula said: *"…you don't have time to think and ask questions. It's like this is it, I've done my job now get out…"* Jackie said: *"I think the oncologists… see so many patients...they can't give you each…special attention so sometimes you feel… you are on a conveyor belt*". Jackie's experience is highlighted within the following field note extract:

Field note extract: Chemotherapy consent appointment between Doctor 1 and Jackie

…doctor filling out consent form [1 min 38 secs] atmosphere feels tense, mainly silent; just hear doctor breathing and the pen on paper. Doctor starts to read through the consent form (almost singing) "*What are we proposing? 5FU, Epirubicin, Cyclophosphamide, Why? To prevent the cancer coming back. What are the side effects?"* Doctor lists; sickness, mouth, bowels, taste, hair loss "*…..this is me saying I confirm I've explained it all to you and this is you saying you agreed to what's being proposed….. So this is my one and that's your one...Good so you're all sorted"*

Clinicians tended to only inform patients chemotherapy infections could kill out of frustration and as a shock tactic, to instil fear and to reprimand. Only CNS 1 spoke about routinely informing patients of the risk of death because: "*…you have to scare them a bit, otherwise, it doesn't hammer home".* It appeared usual practice for clinicians to stress the risk of death from neutropenic sepsis only to patients whom they judged were not taking this seriously or during subsequent consultations with patients who had delayed presenting to hospital with it. Doctor 4 said he informed people he considered: "…*very stoical and the kind of people who don't want to make a fuss* that *an infection left untreated could kill you"* and Doctor 1 said: *"very rarely do I talk about death. I can think of one woman. She was a single … She had two kiddies, one was young and one was in her twenties and she* [daughter in her twenties] *said my mum won't phone, because she won't want to leave the child… I told her. That's why it's so important to* [call the helpline] *because you can die …"* The following field note extract demonstrates how Doctor 2 and CNS 4 stressed the risks of neutropenic sepsis to Adanna who persisted with a desire to go to a wedding in Africa:

Field note extract: Chemotherapy consent appointment between Doctor 2, CNS 4 and Adanna

… during the consultation CNS 4 and Doctor 2 both focused mainly on dangers of infections and associated risks of going to Africa. Both said several times this was serious and life threatening. Words used by Doctor 2 included: "*urgent" "severe" "fatal" "danger."* Words used by CNS 4 included: "*anything can happen" "life-threatening" "serious" "patients have got really ill and more difficult to manage."* Doctor 2 told Adanna she could get ill very quickly, would need urgent treatment and it wouldn't be safe for her to travel. Doctor 2 said during an informal interview, he stopped stressing the seriousness when he felt reassured Adanna had heard the message about risks of neutropenic sepsis and would not travel abroad during chemotherapy.

Clinicians also referred to chastising patients and using stronger language about death, during consultations subsequent to starting chemotherapy. This was with those patients who had delayed or failed to present with symptoms of neutropenic sepsis (See Property one: Holding in the frustration). This was evident within CNS 1's response to Wendy calling her rather than the helpline when she developed a chest infection (See Category four: Relationships core to accessing help). CNS 1 spoke about being: *"… firm and assertive…I do use the words life threatening because otherwise they don't take it as seriously…I felt I had to like say… you should have rung the hotline, this is nearly 24-hours… so she won't be doing that again…"* Doctor 1 also said: *"…once they have kind of disobeyed…that's when I tell them the seriousness* *of it, you really drum it home that people can die…If they don't erm contact us".* Doctor 4 said: *"you do feel like you want to shake them a little bit and I do… tell them off… tell them that if you have an infection once your immune system is down and it's left untreated that it could kill you and I find that using the strength of "it could kill you" is quite a good way of getting people to take it seriously rather than just oh you might be a bit unwell".*

6.1.1.4 Property four: Reality hitting

Patients appeared to be hit by the reality of having a life threatening illness during chemotherapy information sessions. This made it difficult to engage with information about neutropenic sepsis which also sounded frightening. This situation appeared further exacerbated for those possibly more pessimistic about dying due to a recent bereavement or having metastatic disease.

Information about neutropenic sepsis was provided by doctors as part of the chemotherapy consent process, at which point having a life threatening illness appeared to become a reality for many patients. Doctor 1 explained: *"The whole enormity of them coming to see you and you telling them… they've got however many lymph nodes involved and they're going to need chemotherapy and why they're going to need it. I think that's the point at which they kind of grasp that…"* and Jackie said following her chemotherapy consent appointment: *"… it's just all happened so fast…and in the space of two months…it's just come to this…"* The reality of having a life threatening illness also seemed to hit patients as chemotherapy nurses provided chemotherapy information within the busy day unit immediately prior to the first treatment. CNS 8 said information was provided on: *"… the first day of their chemo so it was all very daunting".* Alice found her information session with a chemotherapy nurse: *"…kind of scary… you are in a strange chair, there's other people having different sorts of chemo, they seem to look at different stages of wellness or not".* Following an information session with a chemotherapy nurse Melanie said: *"It does feel a bit like oh god, right so this is it now…"*

It seemed patients who were going through a family bereavement or who were dealing with unexpected bad news about their prognosis were particularly disengaged from hearing information that heightened their fears of dying. This included information about neutropenic sepsis. Wendy, Hannah and Jackie had experienced recent family bereavements. Hannah became upset when she spoke about her brother who: *"…died of lung cancer two years ago* *and one of the things that really upset me was that he suffered so badly….”* and she indicated she found news about heart problems discovered prior to chemotherapy difficult to cope with: “*…I did feel depressed then because I thought well not only have I got the cancer but there’s all the other stuff comes up as well”.* Wendy’s sister died from breast cancer towards the end of Wendy’s chemotherapy treatment and Wendy indicated she did not like hearing about infections during chemotherapy information sessions: “*…because they said you’ve got to get in straight away or you could be dead the next day or something (laughs)”.* Jackie, whose mother had recently died, was observed to appear: “*…worried, subdued, tense, shocked, flat, rabbit in the headlights”* during chemotherapy information sessions. Jackie said: *“…the fact that you have to ring somewhere just for that* [infection]*… I’d feel a bit awkward about it… it brings back home…You are being treated for something serious”.* Jackie also appeared highly anxious during a nurse led chemotherapy consultation as highlighted within the following observation extract:

Field note extract: Chemotherapy information session between Jackie and CNS 7

I met Jackie and her friend in the corridor outside the waiting room, which was packed. Her appointment was 2:30pm on a Friday. Jackie said she felt really nervous about having the chemo... The receptionist showed her into the department, was very kind and introduced her to the nurse. The chemotherapy bay was busy (6 patients being treated) and was manned by CNS 7 with other nurses helping out. The atmosphere was tense and noisy due to chemotherapy pumps alarming, scalp cooling machines and people talking. CNS 7 told Jackie she was sorry, she had run out of chairs, so showed her to a bed. She provided Jackie with lots of scary information about chemotherapy side effects… During the information session, the emergency alarm went off and the nurses all left the bay. Jackie’s friend told me a patient had reacted badly to chemotherapy… As Jackie’s treatment was about to start she looked extremely tense and asked her friend to pass her rosary which she played with during the chemotherapy treatment...

Some patients also appeared unable to hear information about neutropenic sepsis because they were reeling from the shock of needing chemotherapy. Doctor 4 said: “*…it’s still a lot to take in especially if you are going there not knowing if you are going to need chemotherapy”* and Doctor 5 said when: "…*you get told now you are going to start this. I think it's all a bit of a blur to them."* CNS 3 also said "…*the shock…*o*f being said that you've got cancer and explaining* [the chemotherapy] *so it's not really absorbing in the first sitting".* Melanie was a chief executive who sought out information. Her husband said: *"…we were both devastated…the news that we were given was actually this is an aggressive tumour and that it requires chemotherapy so we both knew that this was actually a very different ball game".* Melanie could not remember information about neutropenic sepsis that was provided immediately following bad news about her prognosis. A week later, Doctor 1 said during an informal interview: *"…She's* [Melanie] *coming back today with a lot more questions…The neutropenia question was as if it hadn't been mentioned* [the previous week]". Melanie also indicated during an informal interview that neutropenic sepsis had not previously registered with her as important. Melanie said: "*I'm just astonished that of all the things I've prepared for…We just forgot about the thermometer. It's just bizarre…"* Melanie required time to adjust to needing chemotherapy before dealing with information about neutropenic sepsis and explained: "…*by the time I got here I had kind of got myself through that, again through research and talking to people and I'd kind of reconciled myself to it…"*

Bad news left Melanie unable to hear information about neutropenic sepsis. Some patients were told they had metastatic disease and were provided with information about chemotherapy side effects during the same appointment. For these patients information about neutropenic sepsis appeared to be further bad news they could not cope with. Paula said she was: *"…taken into a room by a nurse who's dishing out all these leaflets and just telling you, well you've got to have this card and take your temperature…she might have mentioned something about white cells and infections but at that time no-one's going to take in all that… information… it was very very rushed... after someone's been told that kind of news… eventually it's going to kill me".* Alice said: *"…everyone was saying oh this is Alice's big D day and we'll find out* [if the cancer has returned], *so I was a bit sort of nervous about the Friday…she* [the doctor] *was like well it's just definitely breast cancer…I was frightened but the diagnosis was a shock… I was in shock then, I mean real shock..."* Alice said she: *"… went through terror…"* Alice's friend also said: *"There is a lot to take in…she was very scared and it's very difficult to hear things, so she knew the number was there but I don't think she felt so easy about calling it as I thought I felt".*

For Sophia, fears of dying appeared particularly enhanced because in addition to having metastatic disease a relative was dying. Sophia said the thought of having to call the helpline with symptoms of neutropenic sepsis was: “… *quite terrifying…”* and she: *“… felt a bit frightened at all the information…that things were worse than I had thought, I thought oh my gosh here I am all this poisonous stuff coming… he* [chemotherapy nurse] *was <u>very very very</u> important about contacting the helpline, the hotline… and I think he said that more than once…”* She elaborated: *“I think realising that I am in a serious position and I did think ooh I wonder if I’m going to get through all this …it was all a bit doom and gloom…”* Sophia, also indicated she could not hear information about neutropenic sepsis because: “…*there is so much going on and you are slightly frightened and I think when you’re frightened your your mind does cloud over you don’t think so clearly”.*

6.1.2 Category two: Getting away with it, wanting normality and control

Patient and carers dealt with fears of neutropenic sepsis by ignoring the risk, thinking it would not happen to them and by taking precautions against catching infections. All patients who developed infections during chemotherapy initially ignored their symptoms and concentrated on normal life. Some patients took increasing risks with infection exposure and reporting as they got away with not being seriously ill and this was particularly evident in those for whom the reality of death seemed more heightened.

6.1.2.1 Property one: Ignoring the risk

Patients and carers appeared to respond to fears of dying from infections by ignoring the risk and were observed to not ask questions about neutropenic sepsis during chemotherapy consultations. Doctor 4 said: *“… infection is usually quite low down on people’s list of things that they are worried about.”* Alice’s friend said: *“…pile on more fear and people won’t hear it* [information about neutropenic sepsis] *they don’t want to know, they’ll just close down”* This appeared to be the reaction of many patients and carers. Lynda said the: *“…thought of the low white blood count hadn’t erm really concerned me at all…even though I knew it could happen ”* and Adanna said: *“…if you are infected you might die… if you …don’t report quickly to the hospital… I don’t even think about it…I know but it doesn’t come to my mind…”.*

Patients who were going through a bereavement or who had metastatic disease, and some carers, appeared to particularly avoid knowing about the risk of death from neutropenic sepsis. Wendy, Hannah and Jackie referred to recent family bereavements. Wendy appeared alarmed she: *“…could be dead the next day…”* from an infection and did not read chemotherapy literature because she did not: *“…think I’m a good reader to digest things in the brain (laughs)”.* Instead Wendy: *“…didn’t think about it* [infections] *didn’t worry about it….If it’s going to be it’ll be…”* Hannah said she: “…*wasn’t frightened by that* [infection] *even though* [name of doctor] *told me you can die… if you do nothing about it”* and was observed to move Doctor 2 on from talking about neutropenic sepsis as detailed in the following observation extract:

Field note extract:	**Chemotherapy consent appointment between Doctor 2 and Hannah**
Doctor 2:	*...so if you’re not well you ring and you get ready to come into hospital straight away and have antibiotics. Because if you do that you will be safe*
Hannah:	*right, yes*
Doctor 2:	*but if you don’t and stay at home and wait and see what I’m like tomorrow the infection could get very severe or even fatal. So it’s important and although it’s a rare problem we want to get you through it safely.*
Hannah :	*yes, the only side effect I’m worried about is permanent hearing loss*

Hannah also appeared to avoid written chemotherapy information she found frightening. She said: *“…there is information in there* [blue chemotherapy book] *which I hadn’t looked at because I felt I couldn’t bear any more”.* Hannah also did not look at the chemotherapy alert card which mentions neutropenic sepsis. She said: “…*I didn’t read that* [the alert card]*... I did think it was for a hospital and that if I was unconscious or something they hopefully would find it in my handbag”.* Hannah and Jackie also spoke about avoiding other cancer information which highlighted their fears of dying. Hannah: *“…didn’t read the information about the general anaesthetic* [for breast cancer surgery] *…I’m glad I didn’t read all that because I’d have worried…one of first side effects …it mentions is death”.* Jackie said: *“…what I found was quite* *daunting was listening to other women's cases and some of them were quite scary… I decided not to read too much of it because… it was frightening…".*

Paula, Alice and Sophia who had metastatic disease also appeared unable to cope with knowing about neutropenic sepsis. Paula indicated she did not read chemotherapy information because fears of dying took over. Paula said: "…*the leaflet, I've never looked at it again. When I first sat there and tried to read it...but it just didn't make sense because the chemo took over, the chemo, the chemo".* Alice said: *"I suppose I haven't let myself think about that* [infections]…*"* and *S*ophia who was also going through a bereavement was observed to avoid talking with Doctor 1 about emotive issues, in a similar way to Hannah as she attempted to lighten the mood:

Field note extract: Chemotherapy consent appointment between Doctor 1 and Sophia

Sophia appeared nervous going in to see the doctor. The consultation started with a general conversation about how she was feeling. The doctor was empathetic about Sophia appearing tired. Sophia stopped this line of conversation by moving the conversation on. Sophia said: *"…good ready to go"* and she understood there would be three chemotherapy treatments, then reassess, then possibly more chemotherapy and radiotherapy. Sophia tried to lighten the mood by saying "*it will be fun".* Lots of information was given by the doctor about chemotherapy side effects. Sophia did not ask questions and jumped in saying: *"OK I don't have any more questions"* and: *"ready to sign".*

Sophia also avoided written information about neutropenic sepsis. During her first interview she said: *"I think I have been avoiding some of that information which is in the car..."* At her final interview having developed two infections she said: *"…I assume there must be statistics. I've never asked…"* and: *"I don't even say the name properly…neutropenic sepsis…so there's a part of me that doesn't obviously want to know that much about it".* Sophia indicated she avoided information about neutropenic sepsis because she could not face up to thinking she might die. During her first interview she found it: *"…hard to believe that in a matter of a day you could suddenly dip. I don't quite believe it but I have to believe it"* and during her final interview she said: "*…I just knew it was important to act fast Yeah but you could get sick very quickly but I didn't think very much beyond that except, Oh God, you know".*

Of concern were Lynda's mother and Zeena's niece indicating their avoidance behaviours which could hinder their ability to help patients access help if they developed neutropenic sepsis (See Category four: Relationships core to accessing help). When speaking about neutropenic sepsis Lynda's mother said: *"I'm afraid sheer cowardliness has kept me away from… becoming more knowledgeable…think it's due to the shock and the stress…I want to do everything to help but I'm terrified of what someone's going to tell me".* She also said: *"... as her mother… it's like a death sentence. Anything that makes that seem more certain… I am reluctant to… I do face up to it inside myself but I don't want the confirmation…some things hit you quite hard."* Zeena's niece who actively pursued information about chemotherapy side effects described a similar response: *"I did know you could die from the chemo thing…Sometimes I do this thing in my head…you don't want to accept it so you just put it in the back of your head or you choose what you want to hear".*

6.1.2.2 Property two: Feeling protected from infections

Patients also dealt with fears of infections by hoping or believing they would not develop these during chemotherapy. Hannah coped with the risk by not associating herself with those who became unwell during chemotherapy. During her first interview Hannah was: *"…shocked at the way… the other patients looked pretty ill and I almost felt like a fraud…"* Hannah spoke later during her end of treatment interview about having: *"… a gung-ho attitude…" to chemotherapy, which she: "…went into it thinking that I wasn't going to suffer like anybody else. I was terribly optimistic or cut off…I didn't want to know that I was going to be ill".*

Jackie, Helen, Zeena and Adanna, also appeared to deal with fears and lack of control over neutropenic sepsis through believing it would not happen. Jackie hoped she would get away with it. She worried: *"…whether I will end up getting a temperature or not feeling too well on these drugs. I'm, hoping it will go really fast … complete the treatment and then… be able to… breathe a sigh of relief".* Jackie also indicated she thought the risk of infections was exaggerated: *"…they do give you the worse sort of scenario… it might not happen…I might not react…to the drugs as badly as… they say (light laugh)".* Adanna also inferred exaggeration of risk when asked if she thought infections would be a problem for her. Adanna said: *"…I don't think so …I'm not the first person to take it and I'm not the last (laughs)". I saw some people having the chemotherapy…they were not laying on the chair…they walk by their legs, so it's OK and I will be no different…".*

Wendy, Jackie, Zeena and Adanna also coped with the threat of neutropenic sepsis through fatalism, which for those who were from ethnic minority groups included designating responsibility to God to protect them. Adanna said: *"God is there he will fight it for me (laughs) I know it will come out fine…"*and *"… you pray not to have an infection"* Zeena said: *"…everything I leave in God's hands…so I'll survive"* and Jackie believed: *"…my faith…that's gonna help me through it as well".*

Understanding of reduced immunity during chemotherapy and fears of infections may have also encouraged beliefs that natural or boosted immunity could protect patients from infections (See Category three: Making the connection) and that infections could be avoided. Doctor 1 said patients often asked about: "…*people who have colds and coughs, should they avoid going out…"* and spoke about an: *"…elderly lady who'd gone through chemotherapy absolutely fine and then she said can I go out now?' and she'd stayed in the whole time".* Most patients and carers spoke about taking precautions to avoid infections and this behaviour appeared exaggerated in patients dealing with bereavement or who had metastatic cancer and in carers who feared infections. Jackie and Wendy had been through recent bereavements. Wendy said: "…*I was keeping myself safe in the house. I only went out a couple of times to do shopping…"* and Jackie: *"…wasn't in places where there were lots of people and if any of my friends had a cold or they weren't well then I would tell them not to come and visit me. Obviously washing my hands and just keeping clean really"* and she said she stayed away from work during her second week following chemotherapy: "…*because you are quite prone to catching infections".*

Alice, Helen and Sophia who had metastatic cancer also appeared to take increased infection precautions. Alice took her: *"…temperature quite obsessively"* and said: "…*I suppose you get infection that's terribly serious you can die but as I said I haven't sort of even entertained the idea. I was like I mustn't get infection, I mustn't get infection…"* Helen said: *"…there was chicken pox going round the school, so she* [her daughter] *stayed away and kept the boys away* *from me and my son, when his daughter had a cold, he didn't come to the house".* Helen decided: "*…if any of them had bugs or anything to stay away…your immune system is not working".* Sophia initially said: "*if you go on the bus during the day you're not standing with lots of people on a tube train at peak time or anything… I'm washing my hands constantly cleaning my face… and so is my husband and my daughter…"* Carers who feared infections and did not want to think about associated risks were particularly protective. Lynda said her mother: "*...brought me a load of masks to wear…*" and her mother said: "*…any infections, any colds would not go near her and she* changed: "*…all the household cleaning materials and hand washing and body washes".* Similarly, Zeena's niece said: *"…they were saying about anyone with a cold… can't go near her because she risk infection"* and: *"I think everyone felt a bit stressed out with me… because I kept saying you can't do this, you can't do that and this has to be cleaned because she could catch an infection easily and we had the anti-bacterial hand wash".* Sophia's husband also said: *"… as soon as I get in the house first thing I wash my hands… I do not want to be the one…bringing in… the viruses".*

6.1.2.3 Property three: Getting away with it

Doctor 2 considered neutropenic sepsis was: *"…one of these uncontrollable risks which we manage by ignoring…"* and Doctor 5 said: *"…if you don't admit it it's not happening".* Some patients appeared to initially ignore symptoms of infections out of fear of what these may lead to. When Hannah developed an infection she had: "*…a dread of what it might be and you don't want to face up to it*" and although Adanna did not develop an infection during chemotherapy she said: *"…when you see that you have fever and you know that this thing can kill you because without going quickly to them to check you and to give you the right necessary medicine one might die and nobody wants to die and you have if you like you didn't go immediately maybe that's who they are".* Jackie said she found neutropenic sepsis information: *"…worrying… if you've got a temperature or you're not feeling well you have to contact them… day or night for them, TO GIVE, … you something for it and that's quite frightening… it sounds serious…"* When Jackie developed symptoms of neutropenic sepsis she said*: "I did feel very ill, that Saturday I felt like death really..."* She did not call the hospital for two days because she hoped: *"…maybe it's like flu and it will get better…"* Many patients tried to make symptoms of neutropenic sepsis go away. They often repeatedly took their temperature in the hope this would go down, possibly because they knew this was a key symptom to report (Category three: Making the connection). Some patients also tried to reduce their fever. Doctor 3 spoke about an: *"…ex-GP, he was rigoring… just took 2 paracetamol didn't take his temperature".* Fayola and Zeena took paracetamol when they developed neutropenic sepsis. Zeena said: "*You try co-codamol, you try this, still the thing is still there*..." and Fayola said: *"…I was like oh I'm fine, this Lemsip is working…"* Lynda, Wendy and Hannah also tried to reduce their temperatures Lynda was: *"…trying to cool down because I thought oh maybe it's just lying under this blanket and I was just boiling up…"* Wendy: *"…ran a cold bath and my temperature went down…"* and Hannah: *"…didn't ring… the 24-hour help centre because I thought perhaps if I drink some fluids my temperature will come down, which it did".*

Some patients may also have ignored symptoms of neutropenic sepsis because they focused on their normal lives rather than thinking about cancer. Some patients continued working for normality. Jackie said: "*…if I'm at home then it's because I'm sick…so going back to work will just give me some sort of normality"* and Melanie continued working during chemotherapy because she thought it: *"… would help me to feel more normal through the treatment…".* Work commitments meant some patients could not afford to be ill when they developed infections or could ignore these. Melanie said: *"… literally a 24-hour period I realised that I was developing a very red and inflamed breast…I was working and feeling fine… but I could see that this was an infection… I noticed it really getting inflamed about one and then I arranged to see the GP so I was with her at five…she made the connections to the unit…so I was here by seven pm".* Similarly, Fayola continued working in a care home to: *"…avoid spending: my days lying in bed and feeling sorry for myself, I have to get myself busy".* Fayola called the helpline from work when she developed neutropenic sepsis and was asked to go to hospital: "*…before five that's when I rang but I haven't finished my shift so I just had to wait until seven to finish…"* possibly because: *"…I'm an agency worker and so it's like work I didn't get paid".* Sam appeared to not have time to be ill due to childcare commitments. By the time she called the helpline when she developed neutropenic sepsis, she was: *"… mentally not in a state to get myself out of bed and to…get clothes on because I had flu like symptoms… I was shaking. I felt very unwell"*. Caring for her children also meant a delay in getting to hospital because Sam was: *"…in bed with my little one just waiting for my husband to come home…"* (See Category four: Relationships core to accessing help).

Delays related to wanting a normal life may have also extended to a desire to be seen as normal by others and to not create a fuss or burden carers with additional hospital visits. Zeena said her niece: *"…always comes, she stays with me and she's got a small baby"* and Helen was reliant on her daughter to take her to hospital, because she was: "*…told to make my* *own way* [to hospital]*".* Sophia gave: "*the impression that I'm coping quite well. So I'm always the first to say don't worry you go, you know, have a normal day".* Lynda's mother said her daughter: *"…didn't want (name of husband) to see her as a sick person, that he found her attractive."* When Lynda developed neutropenic sepsis she said: *"… I had friends staying…they all went to the pub… (laughs) and I stayed at home… so it was like look I'm fine…I'm just a bit…run down at the end of the day...*" When Lynda's Mother spoke about this she thought there was a: *"...desire in those circumstances not to cause a fuss".*

Some patients also seemed to take increasing risks with infections, in favour of a normal life, as they got away with not becoming seriously ill. Lynda: *"…thought I was being careful…as far as you can be around people and I hadn't kind of caught anything…I say that but…the whole Christmas period there was a whole week there of activity where I saw people…. I remember one at least very definitely having a cold or something... and I'd eaten out quite a lot… but I was like ohh I'm fine you know, none of this seems to be affecting me (laughs)".* Escalating risk taking seemed more apparent in patients who had metastatic disease or who were recently bereaved. Wendy whose sister was dying of breast cancer, failed to present to hospital the first time she developed neutropenic sepsis symptoms and came to no harm so appeared reluctant to call the hotline during a subsequent episode because: *"… the first time after I get this I was ill, really I was. I was like frozen and shivering and I couldn't get heat in my body. If I felt maybe something like that I'd have felt Oh well I'd better go in…"* Alice had metastatic disease and did not let neutropenic sepsis get in the way of her birthday plans. She: *"…was on my way to have a facial…[name of doctor] phoned me and said your blood count is incredibly low… you've got to come back today and I refused, I said it's my birthday, I've got things planned I'm not coming to hospital".* Alice went to hospital when it suited her and she appeared to hope she would not come to harm in the meantime by being: *"gentle with myself, I took taxis and I was with a friend … and the next day…she* [the doctor] *rang me again and I said don't worry I'm coming into [name of hospital] now".*

Sophia and Paula, who also had metastatic disease, stopped monitoring their temperatures following chemotherapy. This appeared due to the fact they got away without developing neutropenic sepsis and because monitoring reminded them of their poor prognosis. Paula said: *"…after a couple of weeks you just get bored of doing it* [taking her temperature] *because nothing's happening…so you just don't do it anymore".* Paula elaborated: "*Maybe it's psychological. Maybe it's a reminder that there's something wrong, or there could be".* Sophia like Paula said she was advised: *"I must take my temperature everyday which I'm afraid I haven't done".* Sophia also said: *"The more I know about it* [chemotherapy side effects]*. The more I don't look".* Paula and Sophia also did not allow infections to get in the way of their normal lives and took increasing risks as they came to no harm. Paula had been: "*…acting a normal life…"* and in terms of infection exposure said: "… *I've had a drink and whatever and I don't really look..."* At the start of chemotherapy, Sophia diligently tried to avoid infections. By the end of chemotherapy she said she could not: *"…live in a bubble and I have sat in the theatre with quite God knows how many germs are running around the theatre…..I'm afraid the pleasure outweighs my assessment of risk".* Paula and Sophia also appeared to persistently put up with symptoms of infections because they did not want to acknowledge they were ill. When Paula developed neutropenic sepsis she said: *"I had the fever on the Monday and erm ended up in hospital on the Friday."* Paula also delayed presenting to hospital on a subsequent occasion when she developed diarrhoea. Paula said she was: *"…a stubborn one...(Laughs)… I had diarrhoea for…seven or eight days. But then it really got chronic like. It got to the stage where it was 22 times in a day … I thought no this is enough and that is when I rang the hospital and came in".* Paula said she delayed seeking help because: "*I just carry on like normal. I have since… cause I find if you lie in bed and feel ill you're gonna be ill".*

When Sophia developed a breast infection she: *"…thought well I'm going to the hospital tomorrow morning. So, I didn't go that night".* Sophia got away with it because: *"He* [a doctor at the hospital] *gave me a prescription for some antibiotics … He was playing safe…and within a very short time, I was fine".* Sophia took greater risks when she visited a dying relation abroad following a subsequent chemotherapy treatment. Sophia: *"…defied the hospital slightly…"* because*:* "*…It was just one of those personal decisions...we would just go and say goodbye…."* Sophia developed a chest infection during the visit and was advised to go to hospital by the helpline doctor. Sophia chose to take a risk by taking oral antibiotics obtained from a chemist, possibly because this had worked with her first infection, and took a plane home. Sophia knew she did not take the infection: "*…fully seriously…just whack a few antibiotics down me...* and she realised: *"…the necessity for really finding out, what was going on…"* but she did not want to know because she felt: *"it can't happen to me on top of everything else can it? Surely after everything I've gone through".*

6.1.3 Category three: Making the connection

Infections were not on patients' and carers' radar as likely or important potential side effects during chemotherapy information sessions (See Category one: Playing down the seriousness and piling on the fear) so they focused on more likely side effects commonly associated with chemotherapy such as nausea and vomiting. Patients also apparently did not make or want to make the connection between their possible symptoms of sepsis and infections described to them by clinicians (See Category two: Getting away with it, wanting normality and control). Most patients and carers realised neutropenic sepsis was not a simple infection after patients had developed this and said that had they understood more about it they would have called the hotline sooner. However, preferences differed regarding how explicitly this should be explained.

6.1.3.1 Property one: Not hitting my radar

Neutropenic sepsis did not hit most patients' and carers' radar because they thought of this as an infection they could be protected from, did not make the connection between their symptoms and infections described by clinicians (See Category one: Playing down the seriousness and piling on the fear) and because neutropenic sepsis did not happen immediately after chemotherapy (See Category two: Getting away with It, wanting normality and control).

Neutropenic sepsis was not on many patients' and carers' radar because clinicians minimised this by describing it as an infection (See Category one: Playing down the seriousness and piling on the fear). Clinicians, including Doctor 1 spoke about neutropenic sepsis being: *"…a difficult concept… to explain, to grapple with…it effects the white cells that are going to help you fight infection, they then don't know how long that's going to be for..."* Similarly Doctor 2 said: *"…it's hard to summarise… I've been dealing with neutropenic sepsis for…years and they've never seen it before…"* and CNS 1 said*: "… if you go round the houses about your white cell count … you've lost them …."* Patients were observed to be informed by clinicians they were at risk of infections during chemotherapy because this affected immunity. CNS 1 advised Sophia: "…*when white cells fall you don't have the ability to fight infection…"* and Doctor 1 told Jackie: *"…chemotherapy affects…the cells in the bone marrow that help you fight infection".* Doctor 2 advised Adanna: "…*white cells which protect against infection are low…"* and CNS 6 told Melanie: *"…you're more prone to infection, because the chemotherapy's affecting …your* *normal cells, so the likelihood of the immune system going down… is increased…*" Most patients and carers heard this message. Helen said: "*…it's common knowledge that the chemo batters your immune system"* and Alice's friend knew: "*…your white blood cells are kind of blasted…so you don't have any resistance to infection…*".

Patients and carers did hear the words infection and reduced immunity so often focused great efforts on avoiding infections and believed their natural immunity could protect them and be enhanced (See Category two: Getting away with it, wanting normality and control). However, most did not know what neutropenic sepsis was or how serious it could be. Patients' beliefs about their natural immunity may have been reinforced by clinicians in attempts to reassure (See Category one: Playing down the seriousness and piling on the fear). Doctor 1 was observed to advise Jackie: "*…from what I've seen of you, erm and your general health… and your age, I would think you'll go through this pretty well ... all you get* [chemotherapy side effects] *will be very manageable"* and Jackie said she was: *"…fairly healthy, I'm not somebody who gets lots of colds and coughs … so I'm hoping my immune system is strong enough, to… cope with it".* Doctor 1 also advised Melanie: *"…it's unlikely you will get them all* [chemotherapy side effects] *…I don't think it will be as bad as you fear, it will be fine…" and* Melanie felt neutropenic sepsis would be: *"…very unlikely, I tend to be generally a fairly robust sort of physical person …"* Sophia also found the possibility of becoming seriously ill with an infection: *"…hard to believe because I'm feeling quite sturdy"*. Lynda: *"…had a flu jab before doing chemo… I wasn't really worried because I was in pretty good health*" and Hannah said: *"I've never had many infections in my life…".* Some patients and carers also thought they could boost their immunity by eating a healthy diet. Melanie's husband said: "*…she's been taking juices every day… after she did that you could see that her neutrophils were much, much higher".* Sophia, during her second interview said when her: "*…whites looked a bit low …I've been really trying to eat proteins..."* and Alice relied on her complementary therapist who gave her: *"herbs for everything…she said we'll help boost your immune system".* Most patients were not told if chemotherapy eradicates white blood cells, neutropenic sepsis could not be avoided because as Doctor 4 pointed out during his interview: "*…a lot of the time we never actually find the source of where someone's infection is coming from…we've all got millions of bacteria in our gut so people actually catch the infections from themselves".* Doctor 4 also said: "*…people have sort of misconceptions…get very concerned about going on public transport when they're on chemotherapy*".

Infections were also not on the radar as important when patients developed these because they apparently believed symptoms were only important if they felt unwell and had a fever (See Category two: Getting away with it, wanting normality and control). Clinicians spoke about a fever being the most obvious indicator of neutropenic sepsis. Doctor 3 said this was: *"…a very good indicator…that's the big one"* and Doctor 4 said: "…*the temperature is the main one…"* Doctor 4 spoke about his colleagues going: "…*on too much… about this magic 38 degrees, only call us if your temperature is over 38 degrees whereas you could be home as sick as a dog with a temperature that's normal".* Doctor 4 also said: *"… if you are really, really sick then you can be hypothermic…"* Other symptoms of neutropenic sepsis did not appear as well described. Doctor 1 explained: "…*it's that more subtle feeling unwell without a fever that's more difficult to understand"* and Doctor 4 said: "*I always say if you just feel unwell you can give us a call, I guess that can be quite vague for some people because they're expecting to feel unwell from the chemotherapy…"* Some clinicians spoke of attempts to explain feeling unwell. Doctor 4 said: "*I always say if you feel unwell… a cough…dysuria, anything that makes you worried then just give us a call even if your temperature is normal"* and CNS 2 was observed to advise Sophia that symptoms might include: *"…shivery (hunches shoulders), cold, any sign of infection or a sore throat, cough".*

Advice about symptom reporting was confusing but key messages included a fever and feeling unwell. Doctor 1 was observed to advise Sophia: "… *if you feel unwell or get a temperature you must call any time of the day or night"* Doctor 2 advised Adanna: "…*infections don't normally show up as anything you can see. They just make you feel bad and you start to run a high temperature"* and CNS 6 advised Adanna to: *"…take your temperature straight away if you feel unwell…"* Doctor 1 advised Jackie: "…*if you get a temperature on chemotherapy…you let us know day or night…but if it's above 38 or if you are feeling poorly even if it's not above 38… you let us know…"* and CNS 3 advised: "…*if they spike a temperature of 38 and above or if they notice that it's creeping up that they need to ring us. Also if they are unwell...".* Because patients heard fever and feeling unwell, they delayed contacting the helpline until these occurred simultaneously (See Category two: Getting away with it, wanting normality and control and Category four: Bothering the helpline). Doctor 1 said: "…*they explain it away… it was just once…I felt fine or it never went up. They'd be feeling unwell but then maybe their temperature isn't quite 38… so I didn't need to bother anyone".* In terms of solely having a fever, CNS 1 said: *"…they can forget that having a high temperature is something that is potentially life threatening"* Doctor 1 said*: "…they think it's bit of a fever it's nothing…"* and Doctor 3 spoke about patients who called: *"…they've had a fever, it's been 38, it was 38 an* *hour ago and they've checked it again and it's gone up to 38.5, they don't necessarily feel fluish."* Wendy and Hannah who had suffered recent bereavements and feared infections could not or would not see the connection between a fever without other symptoms and serious infections and delayed calling. Wendy: "*…was just doing a routine check… I had a high temperature. But I felt OK"* and when Hannah got: "*…a temperature at first I couldn't believe it because I thought I've only got a cold and so I kept taking it…"*.

Most patients delayed contacting clinicians because they initially felt unwell without a fever. CNS 2 said: *"…there are some patients who will wait for their temperature to go up to 38 or to 39 or they feel really, really bad …."* Doctor 4 said some patients told him: *"…they felt unwell but their temperature was normal and then they are phoning in maybe a few hours maybe even a day later saying oh my temperature is up now".* Doctor 3 said: *"… a lady rang me saying she was feeling very unwell…had a headache and she felt very warm"* and CNS 3 said: "when they phone, oh I'm not feeling well, I'm feeling hot…" Patients waited for a fever because this enabled them to distinguish between expected chemotherapy side effects and infections which they could not ignore (See Category two: Getting away with it, wanting normality and control) or would not feel a nuisance calling about (See Category four: Relationships core to accessing help). This was especially difficult following the first treatment. Alice's friend said: *"…they were saying…people react differently…. it was not like she'd had chemotherapy before or she has any idea how she should be feeling".* Lynda's mother also said: *"…this is just a whole new world...anything that happens you think oh it's the chemotherapy".* CNS 1 also spoke about patients thinking: "…*this is just part and parcel of being on chemo"* and CNS 3 said: "…*they might be thinking oh this is normal".*

Sophia, Hannah, Zeena and Jackie justified not calling the helpline because they did not have a fever of 38^0C. Sophia said: "…*it was definitely up…but it didn't go up anymore…"* and her husband added: *"…it wasn't 38, 37.5, I said look it's not, it is an alteration…"* Hannah said: *"…my temperature went up as far as 37.8 and I didn't ring them…"* Zeena who had taken paracetamol also would not call the hospital because: "…*the temperature is not so high…"* and although Jackie knew she: *"…could have an infection without a temperature…in my mind I'm thinking well I've haven't got a temperature so I probably don't have an infection".* Lynda delayed calling because she did not initially recognise she had a fever. She described feeling: *"…really cold I was shivering really crazy and I could only heat up with a bath…I had to sort of lie down and cover myself up you know a load of blankets…and then…I was actually getting* *hotter and I took my temperature around that point and I think I was about 80, 38.4…"* Lynda delayed taking her temperature because: "…*I was so cold (laughs)…I knew it would probably be quite low…"* Fayola, like Zeena took paracetamol and her husband said: *"… OK you don't have a fever…" and* Fayola said: *"I was like OK fine, there's no temperature so it might be just a cold".* Melanie and Alice were looking out for infections by monitoring their temperatures and appeared to believe the absence of fever meant they did not have an infection, rather than using this as an excuse not to call. Melanie: "…*was taking my temperature every day, twice a day… it was always 36.3, 36.5.* Melanie said: *"…with the chest infection… I was sick so I wasn't really talking to people…the GP said it was viral … I just thought well there's nothing I can do other than just get over it and I didn't have a temperature so I didn't have the trigger".* Alice said she: *"… felt dizzy on the Friday, Saturday and Sunday…* She also took her: *"…temperature quite obsessively and my temperature never really… went up to 37 even..."* so Alice: *"…thought oh well this is chemo, you know it's just knocking me sideways".* Melanie and Hannah had read the Macmillan BACUP chemotherapy information which advises calling the helpline if: *"You suddenly feel unwell even with a normal temperature".* Melanie said: *"…if I'd have seen something that said if you are unwell for 3 or 4 days…even with no obvious temperature call us. I would have done that. So just suddenly unwell, no it wasn't sudden… I just had an infection".* Hannah also said: "*…my temperature went up as far as 37.8 and I didn't ring them...but it does say in the literature if that you suddenly feel unwell you should ring them…*".

A further reason for neutropenic sepsis not being on patients' and carers' radar seemed related to timing of information provision and timing of neutropenic sepsis. When information was provided about neutropenic sepsis, patients and carers were more worried about imminent side effects commonly associated with chemotherapy (See Category one: Playing down the seriousness and piling on the fear). Doctor 1 said: *"I think people know that they'll lose their hair and they'll feel sick…and it will be absolutely awful..."* Fayola's husband said: *"…I was more worried about…sickness, the hair loss…that we kind of knew would happen but the infection was something that probably might not happen…"* Melanie also appeared to think she was unlikely to develop an infection. Melanie sought out information and worried she: *"…would end up vomiting excessively".* She did not enquire about neutropenic sepsis because: *"…I wouldn't ask a great deal…unless something really worried me".* Some patients were also preoccupied with fears about chemotherapy administration. Jackie asked a chemotherapy nurse: "…*will I feel any effects when the chemo is going in?"* and Melanie told Doctor 1: "…*because I'm a coward and I don't like pain".*

Infections also fell off patients' and carers' radar as important because these occurred around 10 to 14 days after chemotherapy and were not generally spoken about beyond initial chemotherapy information sessions. Paula and Alice who could not hear about neutropenic sepsis whilst reeling from the news they had metastatic disease indicated they would not be alert to infections during the second week of treatment because they did not know there was a risky time. Paula: *"…didn't know about a white count, I wasn't told about that…"* Alice said: *"…I was susceptible to infection was all I knew"* and Alice's friend said: *"...the white blood cells being at their lowest right in the middle of the cycle…I may have had the information given to me but I certainly didn't take that in…. I don't know if Alice did either".* Some patients further believed infections were unlikely to happen to them as they got away without developing these immediately following chemotherapy (See Category two: Getting away with it, wanting normality and control). This view appeared partly fuelled by a lack of knowledge about timing of neutropenic sepsis. Hannah: *"…assumed it would have been about four or five days after the chemotherapy"* and Lynda was: *"…more worried about having that low count in the first few days after chemo".*

Advice provided by clinicians about checking the temperature may have contributed to patients not being alert to infections during the risky time. Doctors tended to advise patients to check their temperatures if they felt hot or unwell, whereas nurses told Wendy to: *"…keep checking it, don't forget to check your temperature…"* and CNS 2 was observed to advise Sophia to: *"…start from tomorrow and once a day and if you feel hot".* Following her chemotherapy consent appointment with a doctor Melanie thought a fever was a: *"…key indicator for the first 24 to 48 hours…"* then CNS 6 advised her to: *"…keep an eye on your temperature. You don't have to take it every day*...." which left Melanie thinking: *"…it's something I need to be aware of right throughout the three week cycle".* Some patients who knew the risky time still did not appear to make the connection between their symptoms and a need to report these (See Category two: Getting away with it, wanting normality and control). Sophia knew: *"…the white blood corpuscle count will …at its worse…the mid period…."* Jackie took the week off work after chemotherapy: *"…because that's the week they were telling me that you are quite prone to catching infections…"* Fayola knew she was most at risk of infections: *"…about 10 days… after your chemo"* and Melanie knew by her final interview she was at most risk: "*…from day 10 to, well it's 14, 16…"*

Because infections fell off patients' radar it may have been helpful to revisit information about neutropenic sepsis. Clinicians though, appeared to underplay the importance of neutropenic sepsis (See Category one: Playing down the seriousness and piling on the fear) by not generally discussing this with patients beyond the start of chemotherapy. Sophia said: "*…at the second and third chemo no-one mentioned this at all anymore*". Patients spoke about being in the chemotherapy, which was a time when they had experienced the first chemotherapy treatment and were observed to visibly relax. Melanie said after her first chemotherapy: "*I feel I'm kind of I'm in it you know, I've had my first… I really thought it was going to be far more erm uncomfortable and difficult…"* Sophia said this was a good time to take in information about neutropenic sepsis: *"…maybe once treatment is underway…That's a good moment then to give another really good pep talk, because also you relax a bit".*

6.1.3.2 Property two: Getting a wakeup call

Clinicians spoke about patients having to experience neutropenic sepsis to take this seriously. CNS 2 said: *"…maybe they have to experience the impact first before they totally get compliant"* and Doctor 3 said: *"… it feels like it takes one episode of a neutropenic sepsis before they truly, truly realise how important it is".* Lynda also said: *"…it doesn't ram home to you until something actually happens".* Most patients and carers understood the importance of neutropenic sepsis and the risks they had taken (See Category: two: Getting away with it, wanting normality and control) after patients became seriously ill with it. Patients and carers then realised or acknowledged that neutropenic sepsis was not a normal infection that could be avoided or easily treated.

Patients who waited for a fever of 38^0C to develop before reporting neutropenic sepsis symptoms described a rapid and frightening deterioration as they developed neutropenic sepsis which could not be ignored (See Category two: Getting away with it, wanting normality and control and category four; relationships core to accessing help). Sam said: *"I felt really good and then very quickly erm I felt unwell and I got a temperature and erm a chest infection… chest pain…I packed a bag knowing that I'd have to go into hospital…I had flu-like symptoms I was shaking..."* For Lynda and Fayola who had tried to make fevers go away, the deterioration happened in A&E. Lynda said this was: *"…scary…I feel like I'm just getting hotter and hotter and could have passed out… I don't know what's gonna happen."* Fayola said: *"…by the time I finish work…and get to the A&E it was something else entirely... I was really feeling* *sick."* Her husband also: *"…could tell that she was really unwell… It was a bit scary at the time".*

Alice had felt unwell for several days before she: *"…got completely dizzy and collapsed on the doorstep …it stopped me in my tracks… if I hadn't collapsed… I wouldn't have rung them*". Alice did not appear confident to call the helpline unless she had a fever. Alice's friend said: "*…she phoned me up in an absolute panic…because she couldn't find her thermometer..."* Zeena's symptoms started with a sore throat. Her niece said: *"…she had a really bad headache… from the day before."* By the following afternoon Zeena: *"…was feeling so bad… shaking… my legs were killing me…couldn't eat…My head was, oh my god, as if somebody was knocking me… and the neck…Fever, when it was high I said yes I need to call…. this is different".* When Sophia developed a chest infection all she: *"…wanted to do was sit in an armchair with my head leaning forward…didn't want to eat". She said: "…my chest was hurting…I couldn't breathe properly… I thought I had lung cancer… It was just so different to how I'd been feeling the day before. It was a very quick downward slide…"* She knew: "*…distinctly, it wasn't my chemo reaction… headache… feeling very very fluey…a high temperature. So I don't know how you would have ignored that…"*.

Although patients understood reduced immunity during chemotherapy increased the risk of infections, most had not understood the rationale for reporting infections was the risk of sepsis. Doctor 3 said: *"…it doesn't seem like they recognise it's serious … they've been told to ring if they've had a temperature so I don't know if it's recognition or if it's more… doing what they're told".* Similarly, Doctor 5 who worked in A&E said: "*…I'm not sure they necessarily understand about neutropenia…but they know that having a temperature is a bad thing".* Clinicians were concerned that telling patients and carers about neutropenic sepsis might instil fear (See Category one: Playing down the seriousness and piling on the fear). Many patients had assumed clinicians had referred to normal easily treatable infections during chemotherapy information sessions. This included Paula who said: *"…I didn't know about a white count, I wasn't told about that…It's like they're putting it as two separate things and it seems so minor the way they explain it…"* Paula felt she was: *"…one of the lucky ones…Because I've come out of that hospital not knowing how dangerous…"* Jackie said: "*…infection could mean anything… because infections people can get… a dose of antibiotics and you are fine…"* Helen: *"….just thought I'd get really sick and it could take longer to get rid of…" and* Zeena's niece thought: "*…they'll just give her medicine and then she'll be OK…"* Fayola also: *"…thought they were* *going to give me antibiotics to go and use at home and her husband assumed: "…it will probably be a case of…giving her some antibiotics… I didn't think it was going to be as serious as her having to stay in hospital".*

Clinicians did not think patients would understand the term 'neutropenic sepsis'. CNS 1 said: *"I don't even say neutropenic because what does that mean to someone…"* and Doctor 1 said: *"…an overwhelming sepsis… I don't know whether people necessarily know what that means".* Patients and carers indicated terms like blood infection, blood poisoning, sepsis or septicaemia created a better understanding of neutropenic sepsis than infection, although preferences for how explicitly this should be explained differed. Patients who sought out information indicated a preference to be told explicitly and unemotionally what neutropenic sepsis was and the risk of death. Melanie said: "*…I go for absolutely detail, I need to know everything".* Before starting chemotherapy Melanie through her own research: *"… found out... my immune system was going to be particularly weak …if I did get an infection …my body wouldn't be able to throw it off and if it didn't get treated then I could actually end up with sepsis…it's life threatening..."* In terms of explaining the risk of death from neutropenic sepsis Melanie said: "*I would go straight to it…"* and when asked to compare Macmillan Cancer Support chemotherapy information with NHS Sepsis patient information Melanie said: "*…neutropenia doesn't mean anything to people…this* [NHS Sepsis information] *is really straight forward, septicaemia another name for blood poisoning refers to a bacterial infection of the blood…] you would understand that, [and puts you at risk…] because you don't mention septicaemia on this one* [Macmillan Cancer Support Information] *or sepsis on the risk of infection, it's all very not direct….I'd be inclined to say simple things like that. This could be blood poisoning; the sooner you have treatment the better the result is so call us immediately".*

Helen and Alice also sought out information, but had metastatic disease, so piling on the fear about neutropenic sepsis appeared to have resulted in their not hearing or wanting to know about this. Alice referred to the chemotherapy alert card: *"…I didn't know what a neutropenic sepsis is, I said oh risk of that whatever that is"* (See Category two: Getting away with it, wanting normality and control). Alice and Helen also expressed concerns at the risks they had taken. Alice realised during her interview: *"…you get septicaemia which is kind of blood isn't it?"* and she had: *"…absolutely no white blood cells...I had no idea… if I hadn't rung the chemo hotline...goodness knows what would have happened…when [name of doctor] said…go and get some antibiotics, I said no, whereas if I had been maybe a bit more aware…*" Helen and Alice also expressed a preference to be explicitly told about neutropenic sepsis. Helen said: *"…nowhere in this paperwork* [patient information] *was this illness"* and after developing neutropenic sepsis she: *"...actually went on the computer and I read up on it myself... I think… it should be explained to them what that illness is…they should be told how dangerous it could be…I would imagine you actually die with it…"* Helen said: *"…the infection could take over your whole body and affect your blood system…"* and she thought the risk of death would: *"…be quite easy to take in because…you would look for it and you would know the signs not just to ignore it and think… this will wear off in a couple of days."* Alice also said: *"…You can't just leave people to assume…"* and: "…*I prefer to be told everything…I don't mind anything spelt out, I'm not good at things kind of chucked at me, which I suppose is what happened".*

Fayola and her husband also sought out information and wanted the hard facts about neutropenic sepsis. Fayola's husband said: *"…the only time…I heard the phrase* [neutropenic sepsis] *was in hospital…"* He asked a nurse: *"…can you please explain to me what it is that she has that's made you wear these masks...explained… neutropenic sepsis… I didn't really understand what they were talking about. But, when they explained… because she can't fight infections right now…that's…when we really understood what's happening…"* Fayola's husband looked neutropenic sepsis up on the internet and realised: "…*your white cells aren't strong enough to fight off infection…I don't know whether it was impressed upon us how serious it could be".* He also said: *"…if it's stressed upon what could happen if you don't call maybe that would make people call a bit sooner".* For Fayola it was: *"… a wake-up call. When I got home I read up on it…because my white blood cell was 0.2 so it was that low. Had it been I just took paracetamol and I didn't go to the hospital… I could have killed myself…I can catch something and I could have died…"* Fayola felt people starting chemotherapy should: "*know what could happen when your white blood cell is low…"* and said *"They did make you understand that it is risky for your white blood cell to be low, you are prone to infection but the seriousness of it I think most people don't know it…"*

It appeared Melanie, Helen, Alice, Fayola and her husband preferred clear factual descriptions of neutropenic sepsis and this also seemed to be the case for other male carers. Sophia's husband searched the internet and understood from the outset: *"...the immune system becomes compromised because the bone marrow is affected, the bone marrow...produce the white cells…the lowering of the cells…means the weaker immune system… internal infections means… your death…infection could mean septicaemia?".* Melanie described her husband as:

"… the kind of person who says they can tell me what to do and I'll just do it, I don't need to know any more…" and he also indicated a straightforward message was better for him. He said clinicians: *"should be braver about it really. Chemotherapy will reduce your blood cell count, if it goes too low and you get an infection, if you get septicemia that could kill you. That's simple really…".*

Some patients who feared and avoided knowing about neutropenic sepsis also indicated they should be told explicitly about this to prevent them ignoring the risk. Hannah said: "...*the trouble with saying things in softer ways is that you don't really take on board the seriousness of it"* and: *"I think now I would call earlier… Because…talking to you about neutropenic sepsis… it does sound alarming…I think I would have taken it on board more seriously".* Sophia also needed to: "…*understand a bit better that people do die of neutropsepticimia…what it meant that day when I didn't have my bloods done…"* Sophia only appeared to take this more seriously when a Doctor in clinic: *"… ticked me off in a sort of fairly nice manner. YOU DIDN'T HAVE YOUR BLOODS DONE? WHAT? ...she was giving me a message".* Sophia also said: "…*when I relate it to myself, I think oh I wonder if I really could have been that ill so quickly if I'd left it another day… I wonder if it's being a bit exaggerated".* Doctor 2 also appeared to correctly deliver a harsher message to Adanna about neutropenic sepsis. He was observed informing Adanna infections during chemotherapy can be fatal to dissuade her from going to Africa during chemotherapy. Following the consultation CNS 4 believed Adanna took the infection risk seriously because: "…*She has listened…accepted our recommendations…knowing the patient ever since she got diagnosed…you establish that relationship..."* It appeared this approach was successful. Adanna said during her end of treatment interview: *"…when I was about to take the chemo I asked the doctor if he can permiss me to go to [Africa] because they have already fixed the date…and the doctor said no… you can't go …I said OK…I called my husband… and they shifted the date."* Adanna knew during her final interview: "…*for the body to fight the infection would be tough and one might lose his own life".*

CNS 3 thought telling patients about the risk of death from neutropenic sepsis may cause them to be: *"…more scared of ringing"* and some patients and carers who avoided information and feared infections indicated they would have preferred a softer message. For Jackie using language that indicated sepsis was enough to get her to take it seriously as demonstrated within the following interview extract:

Researcher: *The problem that people can get is called neutropenic sepsis. Have you heard of that?*

Jackie: *No… So what is that then?*

Researcher: *basically if you get an infection your body can't fight it and you can get a secondary thing happening which is this neutropenic sepsis…it gets into your blood stream*

Jackie: *ahh*

Researcher: *so it's sort of blood poisoning.*

Jackie: Septicaemia.

Jackie knew what septicaemia was: *"…because my mum died from it. I know how serious it is so…I wouldn't have probably waited that long to do something about it".*

Patients and carers who preferred a softer message indicated clear practical advice would assist in managing fears about neutropenic sepsis. Lynda following her admission with neutropenic sepsis was: *"…more aware of it… I appreciate I could catch anything going…you can't fight it off… it's extremely hard to treat and now I'm like oh my god… I suppose you could die from that rather than dying from your cancer".* Lynda said: *"…if they'd said… you could die then that would have freaked me out… if they'd said look this could be a serious thing… you may not even realise you have this…until you actually catch something that floors you…so you have to be careful…I remember…being told…don't worry too much, you know like don't avoid everything…"* Lynda's mother also indicated: "*I'm quite happy to hear what the side effects are if there is some purposeful activity I could engage in and help… tell me this is going to happen and you can do nothing, well that doesn't help anyone really".* Zeena's niece did not know about neutropenic sepsis and when Zeena became ill they: *"… kept going through the side effects and she* [Zeena] *got her booklets and then she said no it's fine".* Zeena's niece: *"… would have called them way earlier"* had she known about neutropenic sepsis. However, when asked if she should be told about the risk of death she said: "*I don't know, maybe…. I think if I did know of that I would have been so scared…*" Zeena's niece was advised: *"… to call as soon as possible but they weren't clearly asked to say that if you do get it earlier then it's better because then she won't be as ill as long…"* When neutropenic sepsis was explained to

Alice's friend she said: *"Well I had no idea about it".* She also felt practical advice, focused on the benefits of acting quickly, may counterbalance a harsher message about the risk of death as highlighted in the following interview extract:

Researcher: *…the white cells…they go low midway between treatment cycles… you are more prone to infection… that can lead to this secondary thing which is this neutropenic sepsis which is a blood infection, so it's septicaemia….basically, that's why we say call us if you have a temperature or you are unwell because people can die from that quite quickly if they become septic....how do you think you and Alice might have felt… if it had been described like that?*

Alice's friend: *I think she would have been in an even worse panic…. though she may have been more careful (laughs). But when feeling a little ill she would have been, I don't know I say in an even worse panic I mean she was really panicked, she thought she was going to die anyway…*

Researcher: *How about…if we…explained what it was and then we said well this can happen but actually…if you get to us we can get the antibiotics in you and deal with it quickly and the likelihood is it won't lead to anything.*

Alice's friend: *That would be alright yes… that would be fine, that would be fine.*

6.1.4 Category four: Relationships core to accessing help

Patients who initially ignored symptoms of neutropenic sepsis (See Category two: getting away with It, wanting normality and control and Category three: Making the connection) often felt extremely unwell by the time they called the helpline and were disinclined to go to hospital for something they believed was probably not serious (See Category one: Playing down the seriousness and piling on the fear). Relationships with clinicians appeared important to accessing help for neutropenic sepsis. These appeared especially important to patients who had metastatic disease or who were recently bereaved. Delays in accessing the service were associated with patients feeling a bother for calling the helpline and especially busy chemotherapy nurses who did not seem to engage with them emotionally or with side effect management. For the participants, delays were also associated with feeling abandoned by the oncology team when admitted to hospital with neutropenic sepsis. Patients appeared more inclined to call the helpline following good experiences of accessing help for chemotherapy side effects and their relationships with carers also appeared important to calling the helpline.

6.1.4.1 Property one: Bothering the helpline

Patients were often slow to access the helpline because they did not want to know about neutropenic sepsis (See Category two: Getting away with it, wanting normality and control) or did not realise the significance of their symptoms (See category three: Making the connection). Delays also appeared more likely if patients had previously felt a bother for calling the helpline or abandoned by the oncology team when they had presented to hospital with earlier chemotherapy side effects. The helpline service was provided by chemotherapy nurses during the day and oncology doctors outside of normal working hours. Some patients did not appear to view symptoms that indicated neutropenic sepsis as important enough to bother the helpline. Patients told CNS 3: "…*I don't want to bother you"* Doctor 1 spoke about patients who: "… *didn't want to bother anyone or didn't think it was important so they don't phone"* and Doctor 4 said: *"…some people will feel quite unwell and they just don't like to bother people".*

Relationships with clinicians appeared important to feeling a bother about accessing help for neutropenic sepsis. Patients seemed disinclined to call chemotherapy nurses who seemed busy, technically focused and uninvolved in side effect management. CNS 2 indicated she did not have time to provide side effect support. She said: *"…every time they come here they should be reminded clearly of monitoring their temperature or themselves for signs of neutropenic sepsis. So if I only have enough time…"* Melanie spoke about chemotherapy nurses who: *"…seemed to be hugely rushed and quite technical…they feel like plumbers… attaching tubes to you…very little continuity between one* [chemotherapy nurse] *and the other and nobody saying well how's it going, are you OK…"* Melanie and Jackie spoke of snatched opportunities to speak to chemotherapy nurses. Melanie said: "…*the only time there's any conversation is when the nurse is having to give you the pink one... And they actually have to sit and inject it… and that's usually pretty banal. So there's no real space for relationship building …"* and Jackie said: *"…that's the only time I had a chance to chat to them* [chemotherapy nurses] *because they have to sit with me for 15 minutes."* Paula said she did not have a nurse-led chemotherapy information session, rather: *"…It was us asking questions"* and Alice suggested this be incorporated into someone's role who knew: *"…the possible* *effects of chemo and they actually… come and talk to you while you are having it...even a volunteer".*

Patients indicated they did not have relationships with chemotherapy nurses that encouraged checking out of chemotherapy symptoms. Sam did not consider calling the chemotherapy nurses when she developed neutropenic sepsis. Sam said: *"…not really…I really rate them but they don't…have that relationship with you…"* and Sophia, during her first interview felt: "*...inclined not to bother the poor nurse in the chemo unit cause, my god they're busy people* and they: **"...***don't know what bits and bobs have gone wrong with me." They just see…she's been on time six sessions".* Some patients spoke about doctors who knew them providing side effect support rather than chemotherapy nurses. Melanie said: "…*all that's left with your monthly discussions with the medic…"* and Hannah said the chemotherapy nurses: *"...didn't really ask me about side effects... but …* [name of Doctor 4] *who I saw every 3 weeks I did talk to him about the side effects … although the clinic was obviously busy he used to give you the impression that he'd got all the time in the world*".

Reluctance to call the helpline was also associated with previous experiences of feeling a bother for calling to check out chemotherapy side effects with clinicians who struggled to manage the service alongside other roles. Doctor 2 said the chemotherapy nurses: "…*don't have somebody dedicated to answer the phone, they can't talk to the patients, they are doing too many patients at once. I think it's very stressful for them…."* Doctor 4 said: *"…if it keeps on ringing that means you can't get into the ward round…"* and Doctor 3 said*: "…it can be a bit of a burden…"* Clinicians also referred to frustrations associated with calls they considered inappropriate. CNS 3 said: *"…some of them* [patient calls] *are just plain nonsense"* and Doctor 1 said: *"…its things that are perhaps trivial that don't need to be called about in the middle of the night…"* Doctor 3 spoke about: *"…over cautious patients… you get calls about sometimes the silliest little things… you are busy clerking in patients, you have ward patients you are worried about… and then some calling the chemotherapy hotline for their appointment date".* Doctor 4 also said: *"You get people phoning up at 3am… …saying oh could you just tell me when my appointment is? …people will phone up…11pm on Friday night saying oh I've been having this pain for the last week*" .

Doctor 3 assumed: "…*obvious complications would be spelt out to them* [patients]*… I'd like to think it's not a case of, any problem ring that number*". However, patients were not given guidance about calling the helpline (See Category three: Making the connection). CNS 7 advised Jackie: *"…there is a hotline number there that you can call anytime if you've got any problems regarding your chemotherapy"* CNS 6 advised Melanie: "…*it's ok to call you're not bothering us"* and Alice's friend was also told: "…*you can phone us any time, it didn't have to be an absolute emergency".* Sam illuminated a possible reason for calling the hotline about appointments because: *"…my chemo card that gives my appointment and it's got the phone number of the chemo helpline on the back… I would have been told earlier on that that was the number to call if there were any problems".*

Doctor 4 said he would: *"…rather be called over something that's silly and not important than them stay at home with a real problem…"* Doctor 2 also suggested clinician's frustrations with the helpline resulted in: "…*some people just don't then respond appropriately".* An apparent impact of feeling a bother for calling the helpline was reinforcement of some patients' beliefs they should not call if symptoms did not include a fever (See Category three: Making the connection). Jackie called the helpline when she developed diarrhoea and vomiting: *"…on the Friday because it was still really bad and I wasn't able to keep any food down… but they said…because it's only five days after the chemo…it's just a bit of a reaction… by Sunday I was really feeling ill. On Monday morning I phoned…they just kept asking have you got a temperature, I said no I haven't…"* Sam: "…*phoned up… to say I feel very unwell and they'd said well what do you mean, unwell. If you're worried go to A&E…"* Sam: *"…didn't have the temperature… But you know I felt terribly terribly unwell..."* Chemotherapy nurses frustrations about being expected to care for patients who became unwell during chemotherapy appeared to also cause Alice and Melanie to feel a nuisance when they attended the chemotherapy day unit for review. Alice said a chemotherapy nurse: *"...screamed at [name of doctor] for not telling them.... they were a bit grumpy about it"* and Melanie said*: "…the nurse on duty…was a little bit dismissive, he didn't quite know why are you here, your GP shouldn't have sent you here, we are going to close down...".*

In addition to feeling a bother, some patients who did not want to go to hospital and whose chemotherapy symptoms had previously turned out to be unimportant told themselves hospital visits for neutropenic sepsis symptoms were probably an unnecessary disruption (See Category one: Playing down the seriousness and piling on the fear) which may have contributed to delays. Doctor 1 said patients were: *"… just trying to get through it all* [chemotherapy] *with as minimal sort of intervention as possible….they're already here lots, for blood tests, for the clinic visit … their actual treatments… they really just don't want to be back in hospital"* and Doctor 2 said: *"…they don't want any more bother".* Delays in recognising (See Category three: Making the connection) or accepting they needed help (See Category two: Getting away with it, wanting normality and control) meant patients also often felt too unwell to go to hospital when they developed neutropenic sepsis. Alice said: *"…when you collapse you are not really feeling like ringing anybody…."* Sam was: *"…mentally not in a state to get myself out of bed …"* Hannah: *"…just wanted to curl up in bed,"* Sophia: "…*wanted to stay in an armchair and I didn't even want to put my head up… just leave me alone…"* and Zeena appeared apathetic when she told her sons to leave her when she developed neutropenic sepsis because: *"…one day I'm going to die…".*

Doctor 3 spoke about patients: *"…who say I'd rather not go there [A&E]… I'll have to wait for 4 hours"* and Doctor 4 said usually: *"… they're not neutropenic… and they have to sit around for four hours. They know it's a lot of hassle and think I'm probably going to be alright so they don't bother".* C*arers* particularly alluded to fatigue associated with hospital visits. Zeena's niece said: *"…we didn't want to just go to hospital for the sake of it and then it's nothing and then we're kept there for long"* and Fayola's husband said: *"…because we'd been through quite a few sessions of chemo and a few things had happened along the line I thought maybe we could probably just leave it for a couple of days..."* Clinicians may have also contributed to some patients delaying getting to hospital with neutropenic sepsis because they did not explain what this was to patients who called the helpline and may have played down the importance (See Category one: Playing down the seriousness, piling on the fear). Doctor 3 said: *"I don't try and freak them out too much I just say we need to get a blood test done so can you get yourself to…hospital as soon as possible…I don't make it seem like they're going to die if they don't unless they're very ill".* Consequently, Sam, Alice and Fayola did not get the message they needed to get to hospital quickly. Sam waited for her husband to come home and: *"…wasn't massively worried. I just knew I needed to get there at some point"* Alice told the helpline: *"I've got an appointment at 4.30pm, she said well you really should go soon. I said well I'll go at 5.30pm"* and Fayola: *"… didn't tell her* [helpline clinician] *I was at work… she said make sure I go straight to A&E and I said OK. I couldn't leave my work".*

Delays in accessing the on-call service with neutropenic sepsis also appeared associated with having to attend A&E departments rather than the more familiar cancer centre. Sam: "…*felt slightly let down because … I was told there was no A&E at [name of hospital]…".* Concerns about abandonment appeared particularly evident for patients who were bereaved or who had metastatic disease. Alice said: "…*although (name of hospital) is open until 6pm, they said go to your nearest Accident & Emergency*" and Hannah and Sophia indicated they may put off calling because Hannah: "…*dreaded having to go to the nearest hospital… are they going to really appreciate my situation"?* and Sophia found it: "…*quite disturbing especially when you have been… nurtured by the breast cancer unit (laughs)…"* Clinicians also spoke of concerns regarding management of neutropenic sepsis in A&E. Doctor 4 said: "…*it's supposed to be door to antibiotics in an hour and that doesn't happen* and Doctor 2 said: *"They need proper expert care, they spend much longer in hospital, they get the wrong antibiotics…*" Doctor 1 recognised: *"…often that's really traumatic for them [patients] … they [A&E] do things differently … it's that sort of scariness of not being under your team".* Doctor 5 who worked in A&E said patients felt: "…*they shouldn't have to come in through A&E…They should go to the oncology centre. I'm not sure I disagree with that…"* Doctor 5 also explained: "… *the person that treats the patient with neutropenic sepsis is an F2 potentially… who doesn't really understand it…"* and CNS 8 who also worked in A&E said the oncology team had: *"…that more specialist training… we're a jack of all trades…"* .

Patients did not have relationships with A&E clinicians and sometimes experiences in A&E contributed to a disinclination to return due to feeling a bother or because of poor communication between clinicians. Fayola was reviewed in A&E several times and when she developed neutropenic sepsis decided she did not: "…*want to keep ringing the hotline and becoming a nuisance..."* Fayola said: *"…they're always nice but it's something in you will feel like oh every little thing you are going to be calling, so I just thought I'd see how it goes…"* Helen attended A&E with: "*… terrible diarrhoea… terrible pains… everywhere… they* [A&E clinicians] *said I had a sore throat, gave me antibiotics and sent me home".* Helen's condition continued to deteriorate and she: *"…was vomiting all day Saturday, all day Sunday, I couldn't eat, I couldn't drink and on the Monday… I actually thought I was dying".* Helen did not call the helpline again because: "…*[name of A&E] said…It's just the side effects….. I thought I can't keep ringing them up every time I feel ill".*

Oncology clinicians promised they would communicate with A&E clinicians if patients were required to attend A&E due to chemotherapy side effects. CNS 6 was observed to inform Melanie: "… *they would talk to the team over here".* CNS 1 said she advised: "…*we will liaise with the team that are admitting you to make sure you get the appropriate treatment"* CNS 3 said she too advised: "…*once there is a bed they will transfer you, they will liaise with the hospital*…" and Doctor 3 said: "…*you are our patient and we will bring you here…"* Liaison between oncology and A&E clinicians did not always happen. Doctor 4 said: "…*we try to give them* [A&E] *a call then and let them know the patient is coming….which can often be very difficult because …no-one wants to take the responsibility for that patient coming in"* and Doctor 1 said: *"…some hospitals you know about it immediately …they're on the phone, they're asking for advice. Other patients, you won't know till they're four, five days in to an admission".* Clinicians who worked in A&E also spoke of poor communication. Doctor 5 when asked if the oncology team called ahead said: "…*sometimes…"* and CNS 8 said: "…*we struggle to get in touch with the… oncologists*…".

Clinicians attempted to fill the communication gap by designating responsibility to patients to present their case to A&E. CNS 1 said she advised: "… *if you are admitted to your local hospital… make it clear with your chemo card that look I'm on chemotherapy… So you're triaged and seen quickly…"* and CNS 2 advised patients to: "… *bring … the blue book… and they have to say that the doctor told them to go to the local A&E and have a blood test and have necessary antibiotics".* Fayola said: *"…the first time I went to A&E they said they were going to ring them but when I got there nobody seems to know why I'm there so I have to be the one to tell them…"* and Alice said: "…*it was fine, I just showed them the card and said the chemo hotline told me to come".* Clinicians who worked in A&E indicated patients who attended A&E with neutropenic sepsis expected clinicians to communicate about their care. Doctor 5 said patients with neutropenic sepsis: "*tend to arrive assuming we know all about them…we often know very little about them" and* CNS 8 said: **"***…you often hear…you've got my records".*

Patients further indicated they lacked confidence in care provided when communication was poor. Lynda said her admission to hospital with neutropenic sepsis: "…*was horrible… it was quite scary because I thought oh god… maybe they don't see me as an emergency…I was transferred onto…an overspill kind of ward… [name of hospital], had said they wanted me transferred but I mean that* <u>*never*</u> *happened".* Oncology Clinicians spoke about worried patients informing them of their admissions to hospital with neutropenic sepsis. Doctor 1 said: *"…That's when it's awful when the patient pitches up saying… I was in Hospital X' and you* *know nothing about it..."* and CNS 1 said: "…*the sensible ones will just ring up the hotline and say oh I landed up in hospital… keep you informed".*

When communication was poor, some patients appeared reluctant to return to the care of A&E. Helen's experience of being admitted to hospital with neutropenic sepsis resulted in her feeling: *"… the care I got in the hospital was terrible and I said I'd never go back in again".* Further, patients who lacked confidence in care provided by other clinical teams appeared to pressurise for review at the cancer centre, which may have contributed to delayed presentation with neutropenic sepsis. Alice was sent home from A&E when she developed neutropenic sepsis because: *"…you haven't got a temperature you've obviously not got an infection..."* Alice said the following day an oncology doctor: "…*phoned me and said your blood count is incredibly low you shouldn't have been allowed out of hospital last night…"* Alice then: "…*didn't want to go back to Accident & Emergency… I rang [the chemotherapy day unit]… and I said to them can I go there…"* Doctor 4 said patients asked to attend the chemotherapy day unit because: "…*they know us here and we know them*". CNS 3 said: "…*they would rather to prefer come here…" and* CNS 2 was told: "...*I like to go there because I like the way you care for us".* Clinicians also suggested patients felt safer at the cancer centre. CNS 2 was told by patients that A&E staff: *"… don't know what they're doing"* and Doctor 3 said patients would: "…*just rather… wait to be seen here as opposed to endure what they've had there".* Doctor 4 also said: "…*things will happen more quickly here so even if it means they have to travel further they'll get here…."*

Patients appeared more inclined to call the helpline following a good experience of accessing help for neutropenic sepsis and when they knew they were seriously ill (See Category three: Making the connection). Patients also did not feel a bother for bypassing the system and checking out their symptoms with clinicians with whom they had an established relationship. Patients viewed the helpline as an emergency service despite being advised to call anytime to check out their symptoms and did not feel a bother for calling about symptoms which they considered serious (See Category three: Making the connection) and could not continue to ignore (See Category two: Getting away with it, wanting normality and control). Fayola's husband said they delayed calling when she developed neutropenic sepsis until: "... *it was starting to get gradually more serious...*" and Jackie said: "…*they told me to call if there's any problem. I just felt it was just for emergencies… because I could see they're busy, they've got obviously people are more seriously ill so I didn't want to ring for the sake of it".* Jackie subsequently delayed calling until: *"… I didn't feel well and I knew something was wrong…."* Paula said: *"…I don't like to cry wolf…"* and called the hotline when she: "… *just didn't care I knew it wasn't normal."* Sophia's husband viewed the service as: "…*a hotline in case of emergency…"* and when Sophia developed a breast infection she: *"… thought of ringing the helpline, but you don't want to do it except as a last resort.... you'd want to be really sure you weren't making a fuss about nothing".* Sophia called when she knew: *"…it was serious enough…there wasn't even any question that I would be bothering them…"* Sam said she felt a bother for calling the helpline because advice about when to call: *"…wasn't very concrete so the second time I, I had to be very sure that I was ill enough to ring up. I think it's quite a fine line. You have to know yourself…*" When Sam developed neutropenic sepsis she: "…*phoned back when I'd got a temperature*". Interestingly, before starting chemotherapy Melanie felt: "…*confident to call* [the helpline] *totally… it's there for reassurance as well as advice... just to check something out*." By her final interview Melanie felt: *"…everybody being so franticly busy would actually put me off… you are not going to make a random phone call just to get reassured, you will make a phone call when you really think you're either in a crisis or there's a real problem".*

Patients also appeared more inclined to access the on-call service after reported symptoms of neutropenic sepsis were taken seriously by clinicians and when they subsequently understood symptoms to look out for (See Category three: Making the connection). When Sophia developed a chest infection she said: *"…they* [helpline doctor] *were very responsive… they were wonderful…"* and Hannah was: "…*very impressed the first time I rang the helpline… and even with a cold the fact that the doctor took the trouble to phone me".* Doctors who had good relationships with Sam and Hannah reinforced risks they had taken by not reporting infections and conveyed the importance of reporting similar symptoms in the future (See Category three: Making the connection). Hannah said she called the hotline with a second infection because: "…*after that first very bad dose of chemo when it really hit me [name of doctor] said I should have phoned them much more and he said we're going to nag you very kindly to phone us…He said it's because if you get a genuine infection it can have serious consequences…"* Sam was told: *"… we've had two people who've been quite ill from Docetaxel and so, you must let us know… So that made me feel okay, it's fine to, I will phone".* When Sam called with a subsequent infection she indicated a positive response encouraged her to call again because: "…*now I've done it and it's actually just a doctor picking up a phone in an office… and… he was dispensing sound advice".*

Patients also appeared to feel less of a bother and got to hospital quicker when they realised symptoms of neutropenic sepsis were taken seriously by clinicians who manned the helpline who also ensured they would be expected and treated as a priority when they got to hospital. Jackie said the: **"…***oncologist had phoned ahead and told the nurses to expect me and to do the blood tests straight away…".* Zeena's niece said a doctor advised Zeena needed: *"… to be put on a course of antibiotics and just to take her straight away to A&E and … we should call the ambulance…they'll let the hospital know to expect us".* Lynda also went to A&E straight away after calling: "*the…helpline and erm they said to me to get to my nearest A&E as quickly as possible and that they would err fax them erm my last eh treatment letter, so that they would know to expect me".* Zeena said: "…*when I went [to A&E] told them that they rang from (name of hospital) and said yes and then just straightaway….they did everything…"* Because Zeena was treated as a priority, got good care and understood more about infection risks (See Category three: Making the connection) she too appeared prepared to come forward earlier in the future. Zeena said: "…*If you leave it then it will take time to get well… but if you call they look after you … give you medicine…*".

Patients also did not feel a bother for waiting to check out symptoms of neutropenic sepsis they suspected or hoped were not important (Category one: Playing down the seriousness and piling on the fear; Category two: Getting away with It, wanting normality and control and Category three: Making the connection) with clinicians with whom they had established relationships. CNS 1 spoke about: "*…a tendency to call the breast care nurses as opposed to call the hotline".* She also said: "*… it's partly because they don't want to bother people that they delay ringing and they like ringing you because they… know you".* Adanna called a breast care nurse when she developed chemotherapy side effects because: *"…they knew me already… That's why I prefer to call them than the 24-hour hotline".* Relationships with clinicians appeared particularly important to patients who had metastatic disease or were recently bereaved. Wendy whose sister was dying of breast cancer called a breast care nurse when she developed neutropenic sepsis because: *"…I didn't think it was that important".* Jackie whose mother died just before she started chemotherapy said her breast care nurse had: "*…been brilliant, she would always return my calls…"* It was therefore unsurprising Jackie: "*…would probably phone [name of breast care nurse]..."* about chemotherapy side effects.*"* Sophia who had metastatic disease considered the breast nurse: "...*was more concerned about me personally* [than the chemotherapy nurses]... *I felt that I could ask her*" and she was: "*…reassured in good hands…"* which may in part account for her waiting until a clinic appointment to report a breast infection. The importance of therapeutic relationships in accessing help was also evident in the account of Alice who had metastatic disease and did not consider calling a breast care nurse when she developed neutropenic sepsis. Alice said she did not have: *"…much confidence and I don't feel I've had a relationship with her [breast care nurse] and I think it's about a relationship…It didn't occur to me to call her…."* Alice also had: "*…an uneasy relationship…"* with an oncology doctor who Alice reported: "*...phoned me and said your blood count is incredibly low you shouldn't have been allowed out of hospital last night, you've got to come back today and I refused, I said it's my birthday, I've got things planned…"*

Paula who also had metastatic disease went to her GP when she developed infections on two occasions. Paula perceived the breast team: *"…gave up on me"* and spoke of not seeing a breast care nurse since her diagnosis: "*That was all the contact you had with her…"* Paula also lacked confidence in the chemotherapy nurses who appeared not to know her case: *"…it's like you're supposed to know that… It's been like one thing after another".* When asked if she thought of calling the helpline when she became unwell Paula said: *"…It didn't enter my head. Go down to the GPs and get some antibiotics".* Helen and Melanie also went to their GP's when they developed infections. When asked about her relationship with the breast and chemotherapy nurses Melanie did not feel she had: *"…a strong relationship with either…"* She said the breast nurses*: "passed me by… because a few times… I did ask them to do something the answer was kind of well we can't… and I just never called again"* and she thought the chemotherapy nurses saw her as: "*…just another face…"* Melanie's confidence and relationship with the cancer nurses diminished when she developed a chest infection. Melanie called: "*… my so called breast nurse … because I was not sure I should have chemotherapy if I'm already this unwell but the answer from her on that day…as well as from the nurse* [chemotherapy nurse]*…was if your bloods are OK you have chemotherapy".* Melanie was given the chemotherapy and did not call the hospital as she became progressively unwell because as her husband said: "*…it's actually to feel that there's actually some competence there … there wasn't really…"* Rather, Melanie saw her GP because: "*…we've seen each other a lot more over many, many more years…, we do know each other. I usually get sense out of her…"* Helen's family also went to her GP after she had been made to feel a bother for calling the helpline. Helen who had metastatic disease said: "*…when I actually had to ring up and speak to a doctor* [helpline]*. I thought this is a waste of time".* Helen's GP had encouraged her to check out chemotherapy symptoms with him and advised her: "*…be very careful…a slight sniffle anything I had to get erm in contact with him straight away"* and when she was seriously ill with neutropenic sepsis he: "...*come out straight away... he was quite concerned… he rang up erm [name of Hospital] and they said I was to come in straight away…".*

Relationships with clinicians who patients trusted appeared core to their accessing help for neutropenic sepsis. It further appeared that provision of ongoing chemotherapy side effect support within therapeutic relationships might promote earlier detection and treatment of this condition. Patients indicated they found it difficult not being in touch with a member of the oncology team between treatments. Jackie had thought a nurse would call her during treatment: "*….because when they said you would be allocated a cancer nurse I thought that's what would have happened but it didn't…"* and Sam found it: "…*quite difficult because ... there's no contact from the time that you have your chemotherapy to your next erm meeting with the doctors three weeks later..."* CNS 3 said if she could proactively call patients during chemotherapy: "…at *least… any neutropenia then it can be treated straight away…" Jackie said if a nurse called: "…it's not left to you … it would be nice if the nurses would phone and just say… how are you feeling because I wouldn't just phone up and tell them how I'm feeling because they are busy".* Helen said: *"Even though they knew I was going to the local hospital, nobody rung at all to see how I got on or what had happened, cos maybe if they had done and my husband would have been able to say how ill I was I might have been, had my treatment a lot quicker*". Alice's friend said: "…*maybe they* [patients] *just need to know that they can just talk about it* [side effects] *they can just phone up and talk to someone and I don't even know if that is possible…"* It appeared a relationship with clinicians to include proactive calling might encourage patients to call to check out their symptoms. Fayola's husband said: "…*it would have been fantastic if there could be someone from the chemotherapy team who would probably just call maybe during the first week of your chemo…to find out how you are doing and to impress on the person again that any problems at all call us..."* Melanie's husband also believed her chest infection would have been treated sooner if someone were: "…*available and will actually get back and support her…had there been a relationship with the care nurse she would have actually called and said this is going on what do you think".*

6.1.4.2 Property two: Carers an untapped resource

Relationships with carers also appeared important to accessing help for neutropenic sepsis. Female carers (friends and family) who attended chemotherapy information sessions appeared able to persuade patients to call the helpline when they developed infections. Male carers (partners and sons) who lived with patients (who had not attended chemotherapy appointments) seemed unable to persuade. Patients found it difficult to identify neutropenic sepsis symptoms (See Category three: Making the connection) and often felt disinclined to act because they ignored their symptoms (See Category two: Getting away with it, wanting normality and control) or did not want to be a bother (See Property one: Bothering the helpline). Carers often noticed significant changes. CNS 1 said: "…*It's the people around the patient who are really good at saying are you alright… maybe you should check your temperature…"* and CNS 3 said carers noticed: "…*that's different from what her was before, another perspective*". Doctor 1 thought carers were: "…*more observant for the problems and side effects…"* Clinicians though, also indicated carers sometimes had difficulties persuading patients with neutropenic sepsis to access help. CNS 3 spoke about carers: *"…trying to convince patients to come to the ward or to ring the ward…it's kind of a bit difficult for them…."* and Doctor 1 said: "*Often the relatives take it on board that it's serious… the patient doesn't want to call but the carers are insisting…"*.

Clinicians advised patients to bring a carer to chemotherapy information sessions. CNS 1 said: "…*I always say if we're going to talk to you about starting chemo bring someone with you…"* and Doctor 4 said: *"I'll usually try and encourage them to bring someone..."* Patients did not though, appear encouraged to bring the person most likely to be around if they became unwell, including male carers (usually partners) who lived with them. Further, clinicians were not observed to engage with carers who attended chemotherapy information sessions to equip them to assist patients to access help should they became unwell during chemotherapy. Alice's friend said: "*I don't really know what is offered for friends and family… I don't think they are equipped in any way…"* Rather, clinicians who manned the helpline spoke of arrangements for getting to hospital being made during neutropenic sepsis episodes. Doctor 3 asked patients with suspected neutropenic sepsis: "… *how are you going to get there…do you have a friend or family member to take you or would you be able to go yourself, if not you may need to call an ambulance"* and CNS 2 said: "…*where are the other relatives? Maybe she can… leave her kids with the relatives or the husband…."* Delays in galvanising carers to assist in getting patients to hospital when they developed neutropenic sepsis were evident in the case of Sam who was: "…*just waiting for my husband to come home so he could care for them* [their children]*".*

Doctor 3 thought: *"… you just have to target family members that take a more direct role with the patient…"* Patients though, wanted to remain in control (See Category one: Playing down the seriousness and piling on the fear) and they rather than their carers usually called the hotline when they developed neutropenic sepsis. Doctor 3 said it was: *"… primarily the patients…"* CNS 1 said: "…*it tends to be the patient*…" and CNS 2 said: "…*mostly the patients*" who called. When Sophia was asked if her husband should have been given more information about neutropenic sepsis, she said: "*No, I like to have it I want all information".* Before her treatment Jackie said her: "*biggest worry…having to depend on other people…"* Jackie retaining control appeared evident when her friend was asked during an informal interview if she felt included in consultations. Jackie appeared to steer the interview away from her friend:

Researcher: *And how have you found coming, do they involve you, do the doctors and nurses talk to you much?*

Friend: *No only today, cos Jackie's been telling me what's what….*

Jackie: *(Jumps in) Yes, yes, but I have another friend as well who came…*

Patients wanted to retain control but some also wanted moral support so chose female carers (friends or daughters) to attend chemotherapy information sessions. Female carers were often able to persuade patients to call the helpline about symptoms of neutropenic sepsis without undermining them, but they had to be persistent. Alice's friend accompanied her to chemotherapy information sessions: "*…to emotionally support me…"* and Alice sought her friend's advice when she developed neutropenic sepsis. Alice's friend said: "*She was panicking a lot… I did have to keep saying it to her… Keep repeating it over and over. Just call them, come on call them, they said you can call anytime…"* Wendy's sister and Zeena's niece accompanied them to chemotherapy information sessions. They recognised symptoms described by clinicians as important, which helped reinforce the message to call. Wendy said: "…*she* [her sister] *made me phone the hospital… I only did it to shut my sister up (laughs)… she just wouldn't give me peace until I got it sorted out… if I had a temperature I had to go straight into hospital…"* When asked how her sister knew that, Wendy said: *"Because she came with me to appointments".* When Zeena developed neutropenic sepsis she said her niece pointed out: *"This is different, because everything the nurse explained to her … if you feel like this….*" Zeena's niece indicated why patients may seek support from female carers during chemotherapy. She explained: "*...boys, they deal with things differently than women … I just felt like I had to sort of be around…she finds it more easier to speak to me…. She values my opinion a lot".* Zeena's niece also highlighted difficulties for carers in persuading patients to call the hotline when normal family roles were challenged. Zeena's niece said: "…*she's like my Auntie and I can't be so bossy to her and say come on we're going…I was listening to her… we were discussing it…I wanted to call them...She felt so hot and then I said to her maybe we should call… up to her really…"* As Zeena's condition deteriorated she spoke of her niece becoming more insistent: "*… no Auntie, no I have to call her because you are just lying on the bed like that, so I said alright then".* In a similar case, Helen's daughter became increasingly concerned and finally took the decision to call. Helen said: "*I'd been so ill over the weekend she'd actually come here first thing in the morning when my husband went to work …she couldn't get me to drink, she couldn't get me to eat and I wouldn't communicate with her. Erm, she said as the day went on I began to look worse and she knew then that it wasn't right and that's when she decided to ring my doctor. If it had been down to me, no I would have just lay there".* Only Melanie's friend failed to recognise the significance of her symptoms because: "*…we were all on the same page that it's a viral infection and I don't have a temperature, there's nothing to be done…"* (See Category three: Making the connection).

Patients' inclusion and exclusion of carers from the chemotherapy process appeared influenced by relationships between gender and carer which were also a reflection of their 'relationship to the patient'. Female carers were all sisters, daughters, and friends whereas male carers were mostly husbands or spouses. Female carers who attended chemotherapy information sessions appeared able to persuade patients to access help for neutropenic sepsis. However, patients who wished to remain in control appeared to exclude male carers perceived unable to provide moral support from chemotherapy information sessions. Lynda said her husband: *"...wasn't at the meetings with the doctors"* and her mother added he: "*…went with her (laughs) to a few things but she said he was more stressed than she…"* Sam excluded her husband because: *"…I don't want him to…he's not very good with needles"* and Melanie chose a friend to accompany her who: "…*wouldn't be phased* by the chemotherapy".

Zeena appeared to exclude her sons to protect them, as indicated by her avoiding clinicians speaking with them about her diagnosis: "*…I said no don't want to put my sons in problem... I'll talk to them nicely then."* Sam and Lynda who were younger than other patients did not recruit female carers for moral support during chemotherapy and managed neutropenic sepsis episodes alone. Their husbands appeared to avoid chemotherapy information (See Category two: Getting away with it, wanting normality and control) and were not alert to signs or potential dangers when Sam and Lynda developed neutropenic sepsis (See Category three:

Making the connection). Sam: "…*asked him* [her husband] *to read the leaflets"* and did not ask her husband to come home early from work when she developed neutropenic sepsis, rather she: *"…told him I was going to [name of hospital] once he was home... because he doesn't know how I was feeling…"* Lynda also said her husband: *"…hadn't read any of that information…"* and when she became unwell he also failed to recognise she needed help. Lynda said her husband: *"… just didn't erm see it as that serious … they all went went to the pub… (laughs) and I stayed at home..."* When Lynda eventually called the hotline she took herself to hospital: "…*I got a taxi… my family and friends and they were all out…*".

Some patients shared written chemotherapy information with male carers excluded from information sessions. These carers noticed when patients became unwell with symptoms of neutropenic sepsis but still appeared unable to persuade them to call the hotline. Sophia showed her husband: "…*the card* [chemotherapy alert card]*…if we need to ring an emergency"* and her husband said when Sophia developed mastitis she told him: "…*no we've got an appointment tomorrow… it was going to be for her to judge how she felt".* Melanie said she: *"…would have talked him* [her husband] *through that* [chemotherapy side effects]*…"* and when Melanie developed a chest infection her husband: *"…kept saying why don't you go to the doctors and she kept saying there's no point... She's quite stubborn when she gets going really…although I didn't really over insist".* Zeena also gave her sons written chemotherapy information and said: "…*they were looking at the computer on the internet..*." Zeena said her sons noticed when she became unwell with neutropenic sepsis because: "…*if she doesn't come out of the bed just know that she's not well…"* They told Zeena: *"…is not good if you get infection…you should call the hospital…I said no…the temperature is not so high…"* Zeena explained her sons turned to her niece to persuade her: "... *said [name of niece] take mum...".*

Lynda and Jackie also appeared to exclude female carers that they perceived unable to provide moral support. Lynda's mother wanted to do: *"…everything to help…"* Lynda may have also sought to protect her because: *"…my mother… is quite emotional about it all"* and Lynda's mother spoke about her daughter, sending her a photograph of her shaved head: *"…so that when I saw her I wouldn't be terribly shocked".* Lynda's mother realised her family knew nothing about neutropenic sepsis and were: "…*dependent on her* [Lynda] *to be more aware of that ….* She also said: "…*I should actually be much more aware of …because if she were with me… and she became ill... we need to know that".* Jackie's sister also did not attend chemotherapy information sessions despite their living near to each other. Jackie spoke about her sister finding her cancer diagnosis difficult, and them both struggling to deal with a recent bereavement. Doctor 1 at the chemotherapy consent appointment said: "*she and her sister…was quite understandably sad. I think a combination of the diagnosis and…just buried her mother".* Jackie gave her sister: "*…the information …all the stuff I was given…"* When Jackie became unwell her sister could not persuade her to call the helpline. Jackie said her sister: "*…saw me on Saturday that I looked really terrible and she said you know you need to go in, I didn't do anything I left it until Monday morning".*

Chapter summary:

Four interrelated categories formed of eleven properties were developed. The core category, to which all other categories related, was Playing down the seriousness and piling on the fear. This suggests that clinicians may have underplayed the seriousness of neutropenic sepsis through a desire to balance frightening patients unnecessarily with encouraging them to call the helpline. Consequently, out of frustration clinicians appeared to pile on the fear about neutropenic sepsis whilst minimising description of it to an infection. This behaviour appeared further associated with a tendency to avoid in-depth discussions about possible benefits and consequences of chemotherapy, including the risk of neutropenic sepsis, through fears of treatment refusal. Patients and carers often appeared to deal with their fears of neutropenic sepsis by avoiding knowing about it and concentrating on preventing infections and normal life. They often did not pay attention to symptoms of neutropenic sepsis when these occurred. Avoidance behaviours seemed complicated by patient and carers believing they should feel unwell with a fever of at least $38^{O}C$ to bother the helpline. Furthermore, clinicians appeared more likely to underplay the seriousness of neutropenic sepsis with patients who seemed to perceive they had a poor prognosis. It was these patients who appeared most pessimistic about their prognosis, most frightened by information about neutropenic sepsis and in whom avoidance behaviours seemed exacerbated. Furthermore, patients from ethnic minority groups appeared more likely to take a fatalistic attitude to their risk of developing neutropenic sepsis.

Relationships between patients, clinicians and carers appeared important to timely or delayed presentation. Patient and carers suggested they may have presented to hospital earlier had they fully understood the seriousness of neutropenic sepsis and the symptoms to look out for. Some patients also continued to believe risks of neutropenic sepsis were exaggerated when they understood this condition and the risks of dying. Finally, some carers were able to influence patient behaviour to call the helpline and some were unable to persuade which may be related to gender and associated relationships with patients.

Chapter Seven: Developing the grounded theory (theoretical coding)

7.1 Introduction

The study outlined within this thesis was driven by anecdotal concerns in clinical practice and the literature that some patients die unnecessarily because they delay presenting to hospital when they develop neutropenic sepsis. The study intent was to establish:

Why do some patients delay reporting to hospital with signs and symptoms of neutropenic sepsis, and what assists patients to present earlier to reduce the effects of neutropenic sepsis?

Ethnography was employed for data collection. Grounded theory was applied to direct data collection and analysis and to develop a theory that was grounded in the data.

7.2 Development of a model to illustrate the grounded theory

Theoretical representation of the research findings were developed through application of a theoretical coding model (Morrow and Smith, 1995) described in chapter four. By applying the model to developed categories and properties presented within the previous chapter, a theory began to emerge from the analysed data. Application of the model provided insight into the processes involved (Glaser and Strauss, 1967) in delayed patient presentation with neutropenic sepsis. The coding framework (Morrow and Smith, 1995) (figure 7.1) required identification of:

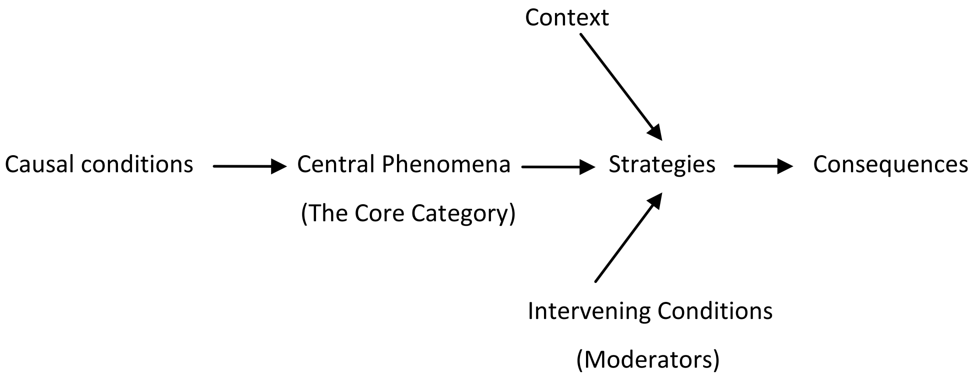
(a) The causal conditions or the underlying components that lead to the responses to the threat of neutropenic sepsis by participants.
(b) The central phenomena or core explanatory category, which provides an explanation for why participants have reacted in the manner described.
(c) The contextual conditions that show how systems and processes might impinge upon the patient's response to delay reporting neutropenic sepsis.
(d) The intervening conditions that show factors that might influence how participants respond to the risks associated with neutropenic sepsis and their reaction to developing neutropenic sepsis. Intervening conditions have also been referred to as moderators within this thesis, in line with the applied Patient-Centred Communication in Cancer Model (Epstein and Street, 2007).

(e) Strategy development, which show the reactions and behaviours patients adopt to deal with the risk and / or development of neutropenic sepsis.

(f) The consequence of strategies patients employ to cope with the threat of neutropenic sepsis which is their delaying presentation when it occurs.

The process was assisted through moving between theory and category development. Application of analytical tools continued until the categories were filled out in terms of properties and dimensions. Applied tools included theoretical sampling, constant comparison, and testing negative views or disconfirming cases, as described within chapter four. Each component of the theoretical coding model is informed by, and draws together, the four developed categories described within the previous chapter.

Figure 7.1. Model framework (Morrow and Smith, 1995)
For permission see appendix 2



7.2.1 Causal conditions or the principal factors that underlie the participants' responses to neutropenic sepsis.

(Informed by findings from the Core Category: "*Playing down the seriousness and piling on the fear"*)

Two types of causal conditions that trigger the central phenomena (the core category) also emerged from data captured within the core category: *"Playing down the seriousness and piling on the fear"*. Causal conditions relate to (a) clinicians fearing patients refusing chemotherapy or dying from neutropenic sepsis and (b) patients being hit by the reality of having a life-threatening illness. More specifically, this suggests causal conditions for clinicians' behaviours include their fearing that being explicit about neutropenic sepsis may frighten patients - who are already reluctant to receive chemotherapy - into refusing it. Clinicians are also frustrated by and do not understand why patients delay presenting to hospital. They worry that patients who develop neutropenic sepsis might die if they delay contacting the hospital. Patient and carer associated causal conditions include those who fear they may die from cancer not wanting to know about neutropenic sepsis. This is complicated because starting chemotherapy, and in particular hearing about neutropenic sepsis, brings home the reality of their having a life threatening illness.

7.2.2 Central phenomena or the core explanatory category that explains why patients react to neutropenic sepsis in the manner described

(Informed by findings from the Core Category: *"Playing down the seriousness and piling on the fear"*)

The central phenomena is also the core category *("Playing down the seriousness and piling on the fear"*) and results from the previously cited causal conditions. "*Playing down the seriousness and piling on the fear"* is designated as the core category due to: (a) its centrality to the theory to explain delayed patient presentation with neutropenic sepsis; (b) its relatedness to all other categories; (c) multiple appearances within the data; and (d) implied relevance to a general theory. Furthermore, the core category allows for optimal variation in dimensions, properties, conditions, consequences and strategies, whilst still representing each case studied (Strauss, 1987).

The Core Category: *"Playing down the seriousness and piling on the fear"* suggests clinicians struggle in attempts to warn patients of the risks of neutropenic sepsis and to convince them to call for help if they become unwell. They adopt tactics which pile on the fear by hinting at the seriousness whilst not explaining what neutropenic sepsis is. This information is provided in a dispassionate way and as a standard repertoire. Information provided about neutropenic sepsis by clinicians makes patients, who are already distressed about having a life threatening illness and starting chemotherapy, feel more fearful of dying and out of control. Patients react by listening but not hearing important information about neutropenic sepsis. Patients instead focus on information about reporting a fever and do not want to take responsibility for reporting neutropenic sepsis.

7.2.3 Contextual conditions or systems and processes that affect patients responses to neutropenic sepsis

(Informed by findings from Category four: *"Relationships core to accessing help")*

Context refers to structural conditions that influence the nature of patients' coping responses or strategies to deal with the central phenomena / core category *("Playing down the seriousness and piling on the fear"*). Responses or strategies emerge through actions, interactions and emotions (Corbin and Strauss, 2008). The category looking at: *"Relationships core to accessing help"* provided some evidence of key contextual influences that affect coping strategies. Contextual conditions were also identified by asking where, when, and how the central phenomena (core category) happened and with whom (Corbin and Strauss, 2008). Contextual conditions relate to: (a) the service infrastructure for delivering chemotherapy; (b) patients' and carers' fears of dying; and (c) poor evidence to explain neutropenic sepsis.

The chemotherapy service infrastructure allows for information about neutropenic sepsis to be mainly delivered to patients before treatment starts. This means patients struggle to hear information about it, because they are concerned about more imminent side effects of chemotherapy such as nausea and vomiting. Furthermore, the service infrastructure and model of care is technically, or drug delivery focused. This does not encourage therapeutic relationships to develop between clinicians' and patients'. In particular, chemotherapy nurses do not form bonds with patients that encourage early reporting of neutropenic sepsis. Patients' and carers' ability to hear about neutropenic sepsis (a life-threatening consequence of chemotherapy) is further confounded because they fear dying from cancer, (a life-threatening illness) and fear chemotherapy.

Patients' and carers' ability to engage with early reporting of neutropenic sepsis is further compromised by the poor evidence available to clinicians' to support their explanations of it. Consequently, patients are reliant on being able to distinguish symptoms of neutropenic sepsis from expected chemotherapy side effects through experiential learning. However neutropenic sepsis tends to occur during early chemotherapy treatments before patients have the experience to recognise "normal" chemotherapy symptom patterns.

7.2.4 Intervening conditions or influencing factors (situational, relational, emotional, cultural, beliefs and values) that moderate patients' responses to neutropenic sepsis.

(Informed by findings from category four: *"Relationships core to accessing help"* and Category two: *"Getting away with it, wanting normality and control"*)

Intervening conditions moderate the nature of patients' coping responses or strategies to deal with the central phenomena / core category *("Playing down the seriousness and piling on the fear")*. Evidence for intervening conditions (moderators) were drawn from Category two: *"Getting away with it, wanting normality and control"* and Category four: *"Relationships core to accessing help"*. Initially, constant comparison enabled development of the theoretical categories and properties within these by comparing *"everything everywhere".* As the research moved further towards theory development, the category dimensions were developed as suggested during the grounded theory summer school by Professor Janice Morse, through "*thinking about these people act like this and these people act like that".* This identified characteristics (intervening conditions) that appear to moderate patients' engagement with reporting neutropenic sepsis. These include having metastatic disease, being bereaved and being fatalistic, which may also be associated with having strong religious beliefs and being from an ethnic minority group. In addition, having a poor relationship with their clinicians and poor or negative experiences of accessing chemotherapy helplines may prevent early patient presentation with neutropenic sepsis. Relationships between patients and carers, and information avoidance behaviours may represent further moderating influences.

7.2.5 Strategies or reactions and behaviours patients adopt to cope with the threat and / or the development of neutropenic sepsis.

Previously cited contextual and intervening conditions influence overarching strategies that are adopted by patients' and carers' to cope with their fears of dying from cancer or neutropenic sepsis. These fears and an inclination to avoid knowing about neutropenic sepsis are also exacerbated by the central phenomena, which is the Core Category: *"Playing down the seriousness and piling on the fear"*. Strategies for coping include: (a) 'avoiding and normalising' and (b) 'acknowledging the seriousness'.

7.2.5.1 Coping strategy: ‘Avoiding and normalising’

(Informed by findings from Category two: “*Getting away with it, wanting normality and control”* and Category four: “*Relationships core to accessing help”*)

The coping strategy ‘avoiding and normalising’ is informed by Category two: *“Getting away with it, wanting normality and control”* and Category four: *“Relationships core to accessing help”*. Fears of neutropenic sepsis for patients and carers are intertwined with thoughts of dying from cancer. Patients who receive information about neutropenic sepsis feel like they are going to die from the cancer. Hearing about neutropenic sepsis heightens these fears further. Consequently, encouraged by clinicians, they avoid thinking about this through adopting normalising and avoidance tactics. Patients try to concentrate on normal life and block and resist knowing about neutropenic sepsis. They focus on infection prevention, put neutropenic sepsis to the back of their minds and think “if and when” they get an infection they might take it seriously. Patients may take increasing risks by delaying reporting neutropenic sepsis if they have previously got away with similar behaviours. Patients may also underplay the seriousness of neutropenic sepsis to male carers (usually partners), so sometimes do not invite them to attend chemotherapy information sessions to avoid worrying them.

7.2.5.2 Coping strategy: ‘Acknowledging the seriousness’

(Informed by findings from Category three: *“Making the connection”* and Category four: *“Relationships core to accessing help”*)

The second coping strategy (‘acknowledging the seriousness’), adopted by patients and carers is informed by Category three: *“Making the connection”* and Category four: *“Relationships core to accessing help”*. Clinicians may unintentionally discourage reporting of neutropenic sepsis symptoms because patients can see they are busy and rushed so do not want to bother them unnecessarily. Patients are further discouraged from calling the helpline if they have previously felt abandoned by oncology clinicians to the care of those less skilled in the management of chemotherapy symptoms. Clinicians encourage patient reporting of neutropenic sepsis by legitimising symptoms that are important to report and by taking responsibility for their care. Female carers (friends and daughters) who attend chemotherapy information sessions, can also legitimise the seriousness of neutropenic sepsis symptoms through shared decision making, but need to be engaged by patients and clinicians to act. Patients underplay how unwell they feel when they develop neutropenic sepsis to avoid worrying carers or making a fuss. Furthermore, they do not want to bother clinicians and cannot face going to hospital. Carers may not initially recognise symptoms of neutropenic sepsis as serious. They may also fear patients dying when they become unwell with neutropenic sepsis, but they have to keep this to themselves and gently persuade them to call the hospital. Carers only feel able to override patients when they become very ill with neutropenic sepsis. When reality hits home and patients realise or acknowledge what neutropenic sepsis is, some take this seriously. Others (especially those with metastatic disease or who are bereaved), cannot face knowing they might have neutropenic sepsis in addition to their cancer, its treatment, and the disruption it has on their lives.

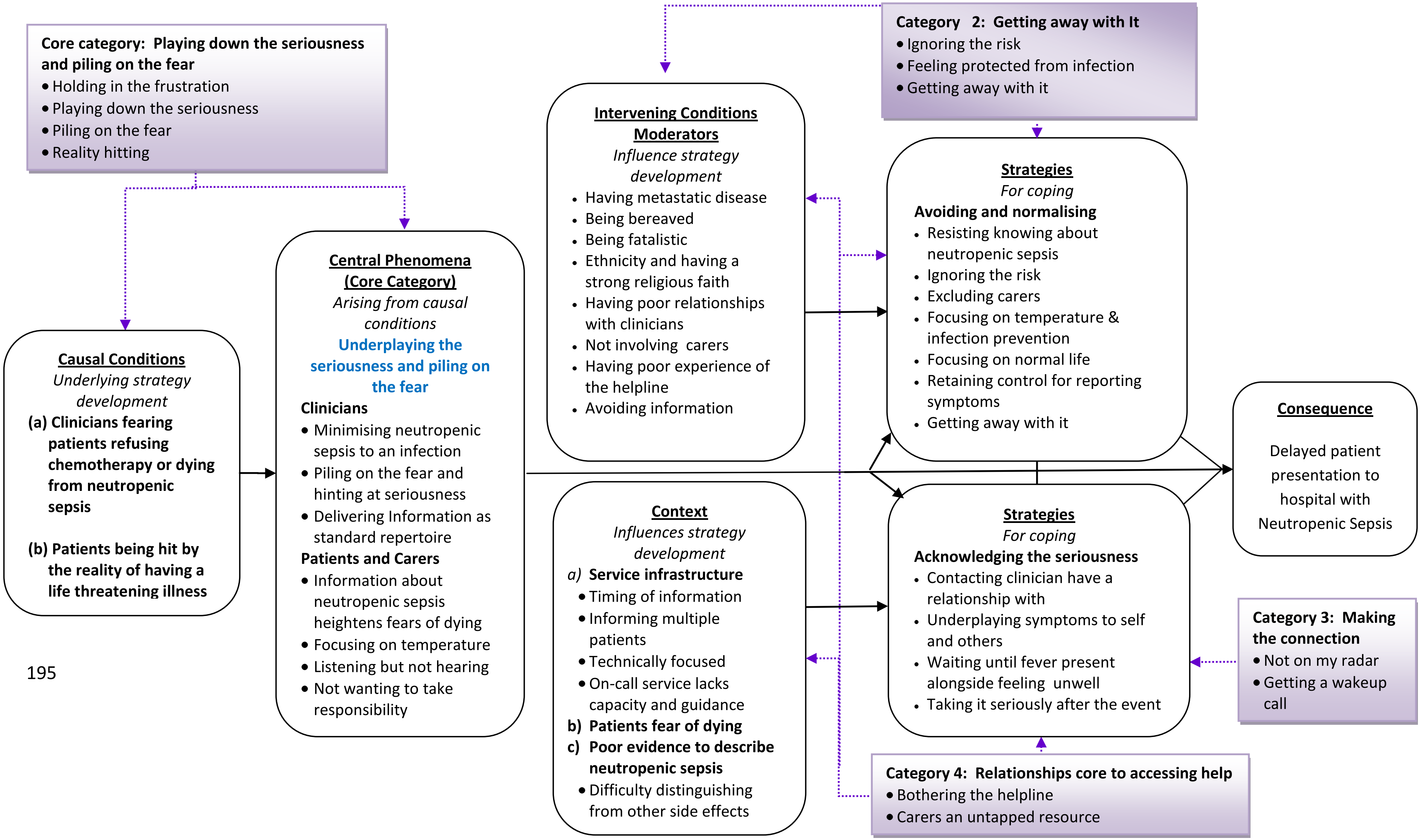
7.2.6 The consequences of strategies used by patients to cope with the threat of neutropenic sepsis

Strategies employed by patients and carers to cope with fears of neutropenic sepsis have consequences for patients. Focusing on normal life may assist them to feel more in control of their cancer and reduce fears of dying. However, a consequence of avoidance behaviours is delayed presentation to hospital when neutropenic sepsis occurs. Importantly, this may put patients at increased risk of morbidity or mortality from it.

7.3 Diagrammatical representation of the theory

A diagrammatic representation of the application of the coding framework (Morrow and Smith, 1995) to study findings is shown in Figure 7.2. This diagram shows the causal conditions, the phenomena, contextual and intervening conditions and strategies and consequences to explain why patients delay presenting to clinicians with neutropenic sepsis. Each of these elements is informed by, and connects, the four categories described within chapter six of this thesis

Figure 7.2. **Grounded theory model for delayed patient presentation with neutropenic sepsis**



7.4 The grounded theory

In summary, what emerges from the data is that there are several interactive factors that affect why patients delay attending hospital with neutropenic sepsis. At the outset clinicians underplay the seriousness or possibility of neutropenic sepsis to patients because they fear this may scare them into refusing chemotherapy. Patients and carers therefore do not easily recognise the seriousness. This is compounded because patients also underplay the seriousness of neutropenic sepsis to themselves because they cannot face knowing about this on top of other fears about a cancer diagnosis. Furthermore, heightened fears of dying occur almost simultaneously with the information giving and consent for chemotherapy.

Some patients underplay the seriousness to their carers by excluding them from the chemotherapy process. This is because they do not want to frighten carers about the risks of neutropenic sepsis or bother them when this occurs. Patients also underplay to clinicians the seriousness of neutropenic sepsis symptoms when these occur because they do not want to acknowledge this is happening to them. Finally, carers underplay their fears about symptoms of neutropenic sepsis when these arise. This is because they do not want to frighten or undermine patients who wish to remain in control of their treatment. Moderators of patients' seeking assistance for neutropenic sepsis include: undertaking information avoidance behaviours, having metastatic disease, being bereaved, being fatalistic which is sometimes associated with relying on god to protect, having poor relationships with clinicians, excluding carers from the chemotherapy process and having poor experiences of accessing help.

Overall, the findings provide evidence for the development of a theory grounded in the data about why patients delay attending hospital with neutropenic sepsis. The final grounded theory to emerge suggests that:

Underplaying the seriousness of neutropenic sepsis is a subconscious collusion between clinicians, patients and carers.

Importantly, the final grounded theory conceptualises the essence of why patients delay presenting to hospital when they develop symptoms of neutropenic sepsis. Underplaying the seriousness of neutropenic sepsis is a behaviour that clinicians, patients and carers are not consciously aware of, but all engage in and is applicable to every participant in this study.

Chapter summary:

The final grounded theory suggests patients delay presenting to hospital when they develop symptoms of neutropenic sepsis. This is because of an unspoken interplay of behaviours where clinicians, patients and carers subconsciously conspire to underplay the seriousness and possibility of neutropenic sepsis occurring. Each has their own reason and perspective for doing so. This theory was refined through application of a model developed by Morrow and Smith (1995) to four identified categories and associated properties (theoretical coding). Causal conditions for the central phenomena include clinicians fearing patients might die from neutropenic sepsis. They also fear treatment refusal if patients know the truth about neutropenic sepsis. Causal conditions for patients relate to their experiencing heightened fears of dying from their cancer during chemotherapy information sessions.

The central phenomena (Core Category), where clinicians underplay the seriousness of neutropenic sepsis whilst piling on the fear (in attempts to persuade patients to make early contact) heighten patients' fears of dying. Strategies adopted by patients to cope with the threat of neutropenic sepsis include avoiding and normalising behaviours. These include patients' focusing on their normal lives and avoiding infections, rather than thinking they might develop neutropenic sepsis. Patients tend to acknowledge the possibility of neutropenic sepsis only when they develop a fever and feel unwell. Many patients only take neutropenic sepsis seriously after having experienced it and thus when they understand more about it through experiential learning. However, some patients, even after experiential learning, continue to feel the risk of neutropenic sepsis is exaggerated. An important contextual factor is the infrastructure which does not nourish healing relationships to encourage ongoing support and self-management. Variations in the process appear explained by intervening conditions that were identified through constant comparison and identification of participants who appear to behave in similar or different ways. Intervening conditions that moderate reporting of neutropenic sepsis include having metastatic disease, being bereaved and being fatalistic, which in some cases include reliance on God to protect. Intervening conditions also relate to relationships between patients and clinicians that cause patients to feel a bother for calling the helpline. Finally, relationships between patients and carers, that appear influenced by gender and characterised by exclusion, also represent moderating influences.

Chapter Eight: Discussion

8.1 Introduction

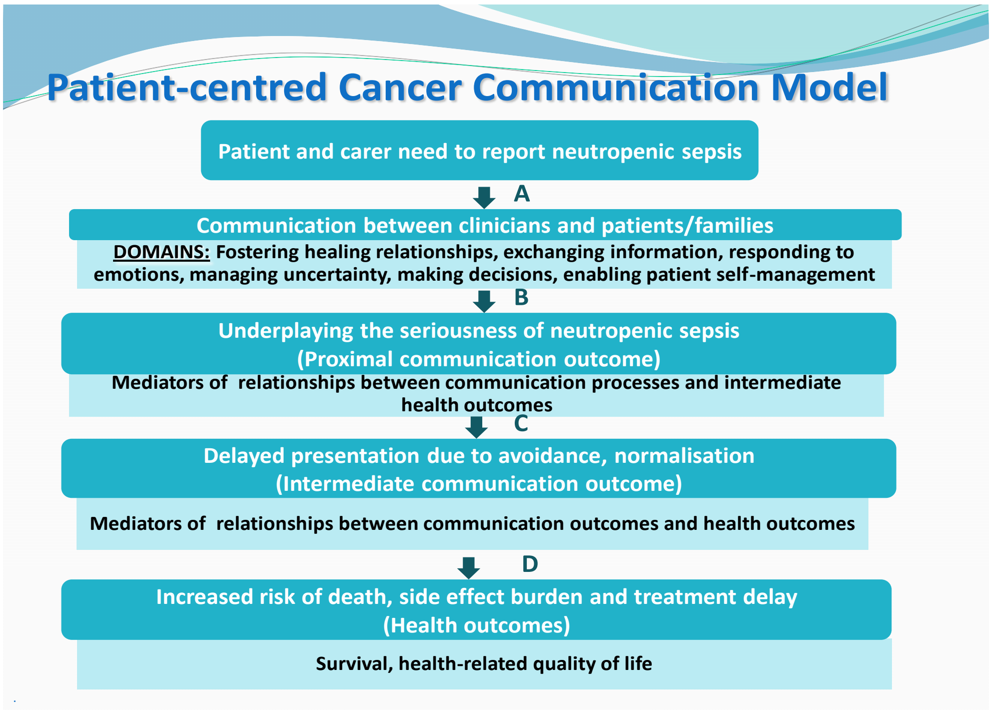
A grounded theory has been developed to explain why patients delay presenting to hospital with neutropenic sepsis. This will now be discussed in relation to the relevant evidence and model of patient-centred communication (Epstein and Street 2007). This is to identify what can be taken from the model to improve the care of patients who are at risk from neutropenic sepsis.

8.2 Applying the model of patient-centred communication to study findings

The PCC model as reported earlier (chapter three), is organised around four mediating pathways that describe the key elements of the process to effective patient-centred communication outcomes. Pathway A is focused on patients' and carers' needs and the mediating relationship of six interrelated domains that represent interactive processes. These domains are: Fostering healing relationships; Exchanging information; Responding to emotions; Managing uncertainty; Making decisions; and; Enabling self-management. The model describes additional moderating factors between patient-centred communication and health outcomes. Pathway B suggests effective patient-centred communication may lead to proximal communication outcomes such as trust and effective information exchange. Next, through pathway C, intermediate outcomes may for example include patient engagement with self-management activities. Finally, pathway D indicates the impact of the mediating process on overall patient health outcomes that include survival and health related quality of life.

The pathways of the PCC model show a good fit with the findings from this grounded theory study and this will be discussed in detail. In summary it has been demonstrated that communicating effectively with patients and their carers is fundamental to decreasing delayed patient presentation with neutropenic sepsis. This is shown in figure 8.1 where the outcomes of communication about neutropenic sepsis are transposed onto the PCC model. Findings will next be explored in relation to how the findings fit with each of the six PCC mediating domains. Where similar observations have been made in other studies these are summarised within table 8.1, along with the unique contributions of the observations from this grounded theory study. The table (8.1) also includes summaries of four theories that underpin the PCC model, and appear pertinent to delayed patient presentation with neutropenic sepsis. These are self-efficacy theory (Bandura, 1977), self-determination theory (Ryan and Decci, 2000), the 5A's for patient-centred counselling (Glascow et al., 2003) and Illness and uncertainty theory (Mischell, 1988).

Figure 8.1. **Applying the grounded theory to the PCC Model (adapted from Epstein and Street, 2007; p43). For permission see appendix 2**



Patient-centred Cancer Communication Model

Patient and carer need to report neutropenic sepsis

A

Communication between clinicians and patients/families

DOMAINS: Fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, enabling patient self-management

B

Underplaying the seriousness of neutropenic sepsis
(Proximal communication outcome)

Mediators of relationships between communication processes and intermediate health outcomes

C

Delayed presentation due to avoidance, normalisation
(Intermediate communication outcome)

Mediators of relationships between communication outcomes and health outcomes

D

Increased risk of death, side effect burden and treatment delay
(Health outcomes)

Survival, health-related quality of life

Table 8.1. Comparison of findings with the patient-centred communication in cancer care model and other studies supporting these

Domain one: Fostering healing relationships		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
Clinicians: • Therapeutic relationships that include trust, honesty, openness and disclosure increase likelihood of patient adherence with self-care activities. • Male and female clinicians may communicate differently with patients. • Communication may depend on patient ethnicity, gender, age or educational status. • Should foster understanding of roles and responsibilities and negotiate goals.	**Clinicians:** • Busy service, focused on technical care at the expense of developing relationships with patients. (1-7) • Do not routinely engage with carers about cancer (8-10) or chemotherapy. (12-13) **Patients:** • Feel processed through chemotherapy systems. (1-2) • Passive in chemotherapy side effect management. (14) • Do not want to bother busy clinicians and inclined to put up with subsequent chemotherapy symptoms if made to feel a bother. (15-16) • May lose trust if oncology clinicians do not take responsibility for serious chemotherapy side effects. (15) • May taking increasing risks if consequences are not apparent with non-adherence to oral chemotherapy (17) or with life-style advice following a myocardial infarction. (18)	**Clinicians:** • Lack of ongoing engagement with patients. • Gender of clinician or patient ethnicity, gender, age or educational status not observed to affect communication between clinicians and patients about neutropenic sepsis. **Patients:** • May delay reporting neutropenic sepsis, by bypassing the system and contacting a clinician they have a relationship with.

References: 1. Van Der Molen, (2000). 2. Mcilfatrick et al., (2006). 3. NCAG, (2009). 4. Pilgrim et al., (2009). 5. Francis, (2013). 6. Maben et al., (2007). 7. Maben, (2008). 8. Morris and Thomas, (2001). 9. Northouse et al., (2010). 10. McCarthy, (2011) 11. Hilton et al., (2000). 12. Ream et al (2013b). 13. Royal College of Physicians, (2012). 14. Bakker et al.,(2001). 15. Dubois and Loiselle (2009). 16. Pedersen et al., (2012). 17. Eliasson, (2011). 18. Wiles and Kinmonth, (2001).

(Table 8.1. continued)

Domain two: Exchanging information		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
Clinicians should: • Understand patients' knowledge, beliefs and concerns. • Tailor information (does not always happen). • Convey key facts, rather than overwhelming. • Use plain English and summarise. • Check understanding through PCC behaviours, e.g. open ended questions, empathy and active listening. **Patients:** • Should understand information provided by clinicians including the rationale for healthy behaviour. • May seek or avoid information.	**Clinicians:** • Deliver chemotherapy information as a tick box exercise (25) and in busy day units which compromises information exchange. (19) **Patients:** • Struggle to absorb information about chemotherapy side effects because they fear having cancer and chemotherapy. (19-23) • Can become overwhelmed by chemotherapy side effect information. (19-22) • May choose to intentionally not adhere to medical recommendations based on own priorities and take increasing risks if consequences are not apparent. (17, 18, 21, 26-28) • Having metastatic disease is associated with avoidance and passivity during cancer consultations. (29-33)	**Clinicians:** • Deliver information as a standard dispassionate repertoire and assume compliance. • Timing of information about neutropenic sepsis may be important. • Lack evidence to describe neutropenic sepsis and symptoms of it to patients. **Patients:** • Find information about neutropenic sepsis can bring home the seriousness of a cancer diagnosis. • May avoid knowing about neutropenic sepsis because this exacerbates fears of dying. • May take increasing risks with infection prevention, monitoring and reporting as they "get away" without coming to harm. This may be exacerbated in those with metastatic disease or who are bereaved, possibly because they are more fearful of dying.

References: 19. Treacy and Mayer, (2000). 20. Skalla et al., (2004). 21. McCaughan and McKenna, (2007). 22. Rimer, (1984). 23. McCorkle and Ehlke, (1992). 24. Dodd and Mood, (1981). 25. Ream et al., (2013a). 26. Thorne, (1999). 27. Rhodes and Cusick, (2000). 28.Rhodes and Cusick, (2002). 29. Pollock et al., (2008) 30. Cassileth et al., (1980), 31. Butow et al., (1997) 32. Mills and Sullivan, (1999) 33. Fallowfield et al., (1995).

(Table 8.1. continued)

Domain three: Responding to emotions		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
Clinicians: - Should elicit emotional concerns before delivering information (through sensitive questioning and responding with constructive help and empathy). - Often miss emotional cues and focus on physical aspects of health care. **Patients:** - Illness representations may differ to clinicians (These are shaped by past experiences, beliefs, emotions, goals, others' experiences and information provided by clinicians). - May deal with fears of cancer and lack of control through avoidance.	**Clinicians:** - May avoid emotional interactions with patients during chemotherapy and focus on physical care. (1, 38, 42) - May encourage inaccurate illness representations of chemotherapy. (17-18) **Patients:** - Fear a cancer diagnosis and starting chemotherapy. (34-36) - Can associate starting chemotherapy with being seriously ill. (37) - May avoid chemotherapy information that is confusing or distressing. (21) - May view chemotherapy side effects as not personally relevant. (29, 39-41) - May adopt normalisation tactics to cope with chemotherapy. (34, 37) - Female carers may provide more moral support than male carers (partners). (13, 43-44)	**Clinicians:** - Avoid informing patients about the risk of death from neutropenic sepsis. - Pile on the fear and underplay the seriousness to patients of neutropenic sepsis. - May encourage patients' illness representation of neutropenic sepsis as unlikely, preventable and easy to treat (an infection not sepsis). **Patients:** - Hearing about neutropenic sepsis may heighten fears of dying for those who are already fearful of dying from cancer and chemotherapy (exacerbated with metastatic disease and bereavement). - May cope through adopting avoidance tactics (incorporated within PCC domain) and normalising tactics (not incorporated).

References 34. Mitchell, (2007). 35. Siminoff and Step, (2005). 36. Ream et al., (2013a). 37. Cowley et al., (2000). 38. Farrell et al., (2005). 39. Ream and Richardson, (1996). 40. Pedersen et al., (2012). 41. Dodd and Ahmed, (1987). 42. Dennison, (1995). 43. Schumacher et al., (2000). 44. Ockerby et al., (2012).

(Table 8.1. continued)

Domain four: Managing uncertainty		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
Illness and Uncertainty Theory (Mischell and Braden, 1988) that Informs the Domain: Uncertainty during illness is the inability to make sense of illness related events, or to accurately predict future illness events and outcomes. Uncertainty is affected by the stimuli frame (the ability to produce a mental schema of events) cognitive capacity (ability to process information) and structure providers (that through education, social support or credible authority enable patients to become familiar with likely illness related events). **Clinicians:** • Should target information to individual patient needs. • May exacerbate patient uncertainty through information overload. • Context and an agreed plan for dealing with uncertainty may moderate and assist patients to manage it. **Patients:** • Confidence may reduce where clinicians express uncertainty. • Relationships with carers, other patients and clinicians can modify uncertainty.	**Clinicians:** • None. **Patients:** • May hold pre-conceived negative views of chemotherapy. (21) • Information about chemotherapy side effects can be overwhelming and confusing. (2, 20) • May not know the chemotherapy side effects to watch for, or the severity to expect. (40 45) • Not knowing what to expect from chemotherapy may reduce perceived control. (45-47) • Dramatic, unexpected nature of neutropenic sepsis can be frightening. (20, 48)	**Clinicians:** • Do not modify information to patient's educational ability. • Relationships with clinicians and carers are not optimised to assist patients with uncertainty about which symptoms to report and when. **Patients:** • Uncertainty about what to expect and preconceived fears may increase anxiety and reduce feelings of control and ability or willingness to hear about neutropenic sepsis or to engage in related self-management.

References: 45. Mishel and Braden, (1988). 46. Mischel, (1990) 47. Stiegelis et al., (2004). 48. Henman et al., (2002).

(Table 8.1. continued)

Domain five: Making decisions		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
• Most patients prefer to make decisions in partnership with clinicians. • Patients tend to weigh up the pros and cons of taking a particular course of action drawing upon beliefs and information available to them.	**Clinicians:** • Do not discuss 'pros and cons' of having chemotherapy with patients. (1, 37, 48-50) • May withhold information about chemotherapy side effects to avoid worrying patients (Paternalism). (37, 50) **Patients:** • Feeling out of control with decisions to have oral chemotherapy may result in non-adherence. (53) • May not know their personal risk of developing neutropenic sepsis. (51) • May not have enough information to manage chemotherapy side effects. (52)	**Clinicians:** • Fear patients will refuse treatment, so do not discuss with them the advantages and disadvantages of having chemotherapy, including open discussion about neutropenic sepsis and personal risk. **Patients:** • Lack of motivation to have chemotherapy may affect patients' ability to hear about neutropenic sepsis and willingness to engage with associated self-management. • Struggle to make decisions to call clinicians about chemotherapy symptoms. • Indicate cognitive impairment (chemo brain) does not affect decision making to report neutropenic sepsis.

References: 49. McCaughan and Thompson, (2000). 50. Lerman et al., (1990). 51. Leonard, (2012). 52. Mazor et al., (2012). 53. Atkins and Fallowfield, (2006)

(Table 8.1. continued)

Domain six: Enabling self-management		
PCC model	**Other studies supporting findings**	**Unique contribution of this study**
Theories that inform the domain: **Self-efficacy theory (Bandura, 1997)** Personal motivation to change a behavior, driven by a personal belief in ability to achieve the change or a specific goal. Low self-efficacy and response efficacy may be associated with reduced intention to act. **Self-Determination Theory (Ryan and Decci, 2000)** Relates to motivating patients to draw on intrinsic resources to act in healthy ways. Three basic innate psychological needs should be fulfilled to be self-determined. Needs include relatedness (to experience reciprocal caring relationships, usually with clinicians), competence (mastery) and autonomy (to feel in control and responsible for ones' own life). **Five A's for Patient-Centred Counselling (Glascow et al., 2003)** Assess, Advise, Agree, Assist, Arrange model of behavioral change which aims to help patients develop personal action plans.	**Clinicians:** • None. **Patients:** • None.	**Clinicians:** • Deliver confusing, frightening information about neutropenic sepsis to patients. They minimise it to an infection. • Do not encourage a self-management approach to enable patients to report neutropenic sepsis. • May encourage early presentation through legitimising symptoms and taking responsibility for their care. **Patients:** • Do not take neutropenic sepsis seriously. • Not engaged with advice/instructions of clinicians to urgently report symptoms of neutropenic sepsis to chemotherapy help-lines. • Struggle to recognise symptoms of neutropenic sepsis. • Focus on reporting a fever.

8.2.1 Domain one: Fostering healing relationships

Findings of this study and other research support the importance of the PCC 'fostering healing relationships' domain to the final grounded theory. A Canadian interview study (n=40) identified that women with cancer who did not feel connected with clinicians adopted passive and submissive roles during chemotherapy consultations (Bakker et al., 2001). Other studies conducted within the UK (Van Der Molen, 2000, Mcilfatrick et al., 2006) further indicate that the chemotherapy system can feel like a factory to patients. A small qualitative study (n=6) found patients felt processed through a busy chemotherapy system (Van Der Molen, 2000). A further phenomenological study conducted with 10 carers identified a "dehumanising element" to chemotherapy treatment delivery. Chemotherapy nurses were focused on efficient delivery of chemotherapy and not the needs of individual patients and carers (Mcilfatrick et al., 2006).

Clinicians from this study who appeared too busy to develop therapeutic relationships with patients reflect a national picture. Chemotherapy usage across the UK increased by 60% between 2002 and 2007 (NCAG, 2009). This means chemotherapy nurses in particular are likely to find it increasingly difficult to get to know patients who pass through their service. Furthermore, a factory mentality observed within this current study was possibly influenced by the recession driven NHS cost reduction programme. Quality measured through targets focused on chemotherapy waiting times, and financial reward is proportional to the number of patients treated rather than the quality of care provided. Similar findings are identified in a literature review of mental health services (Pilgrim et al., 2009). The review identified that a focus on health service targets detracted from the importance of relationships between patients and clinicians in improving mental health (Pilgrim et al., 2009).

This finding is described at an extreme level within the Francis report of the Mid Staffordshire NHS Foundation Trust Public Enquiry into poor care at Stafford hospital (Francis, 2013). The Francis report highlights exhausted staff working within an organisation focused on targets at the expense of patient-centred care. Key in the Francis report was identification of a prevalent lack of organisational compassion towards employees and many recommendations concern increasing compassion within nursing. Research into compassionate care within nursing and medicine also highlights that clinicians are usually intrinsically driven to care for others in an empathetic and compassionate manner. When healthcare infrastructures and cultures do not facilitate compassionate care, intrinsic motivation can be compromised or crushed leading to burnout, reduced job satisfaction, ability to empathise and poorer clinical care (Maben et al., 2007, Maben, 2008, Epstein and Street, 2007). Importantly, for the findings of the current study, Maben's work with newly qualified nurses particularly indicates busy technically focused working environments are not conducive to promoting or sustaining compassionate care (Maben et al., 2007).

Advocacy, in terms of clinicians acting in the best interests of patients, is a core component of the PCC enabling self-management domain. Furthermore, trust is an intermediate outcome of patient-centred communication and may be important to adherence (Epstein and Street 2007). However, findings of the present study concur with conclusions from a National UK, consultation with clinicians. This suggests that substandard care and loss of patient trust may result when oncology clinicians do not take responsibility for patients admitted to A&E departments with neutropenic sepsis (Royal College of Physicians, 2012). The effect of lost trust and being made to feel a bother by clinicians on patients' willingness and self-efficacy to present with symptoms of neutropenic sepsis on subsequent occasions supports other research (Dubois and Loiselle, 2009, Pedersen et al., 2012). A small phenomenological study conducted in Denmark with nine patients also found some would rather not contact clinicians when they developed chemotherapy symptoms (Pedersen et al., 2012). Furthermore, a mixed method Canadian study that included patient completed questionnaires (n=250) and follow-up interviews (n=20) identified patients who felt "fobbed off" and a "nuisance" when accessing help for chemotherapy side effects, which resulted in beliefs that they should put up with subsequent symptoms (Dubois and Loiselle, 2009). Additional findings of the current study also suggest patients may wait to check out symptoms of neutropenic sepsis with clinicians they consider they have a relationship with, rather than reporting symptoms to emergency helplines.

8.2.2 Domain two: Exchanging information

Findings from this study supports other research, that identifies patients with cancer who could not recall information provided by clinicians about chemotherapy side effects (Rimer, 1984, McCorkle and Ehlke, 1992, Treacy and Mayer, 2000, Skalla et al., 2004, McCaughan and McKenna, 2007). This is because patients become overwhelmed by having a cancer diagnosis, starting chemotherapy and information provided about chemotherapy side-effects (Rimer, 1984, Treacy and Mayer, 2000, Skalla et al., 2004, McCaughan and McKenna, 2007). Within one study, two nurses who share their personal experience of having cancer report being unable to recall any information provided to them about chemotherapy, including expected side effects (McCorkle and Ehlke, 1992). Furthermore, only 10 of 30 patients who completed a questionnaire following chemotherapy information sessions were able to name infection as a potentially fatal side effect (Dodd and Mood, 1981). A UK action research study (Ream et al., 2013b) included non-participant observations of interactions between clinicians, patients and carers. Findings replicate those of the current study because clinicians structured their chemotherapy information delivery around checklists, instead of checking patient understanding and tailoring information to the individual (Ream et al., 2013b). A literature review to identify cancer patients' information needs also concluded that delivering chemotherapy information to patients within busy clinical environments may compromise effective information exchange (Treacy and Mayer, 2000).

New evidence from this study suggests that patients struggle to hear information about neutropenic sepsis because this heightens their fears of dying from cancer. This situation appears to be exacerbated by clinicians who deliver information in an urgent and dispassionate manner and at the wrong time (before chemotherapy starts). At this time patients are preoccupied with fears of dying from cancer (See Domain three: Responding to emotions), chemotherapy administration and more imminent chemotherapy side-effects than neutropenic sepsis. Transfer of information about neutropenic sepsis is also complicated by poor evidence to enable clinicians to clearly explain this and early symptoms of it to patients.

It has been suggested that people cope with threatening situations in one of two ways. They either seek out information (monitoring behaviour) or avoid any information relating to the potential threat (blunting behaviour) (Miller, 1995). This implies that information seeking behaviours are fixed or static. As discussed within chapter three of this thesis, in reality this is often not so clear cut because information seeking or avoidance behaviours may change depending on circumstances (NICE, 2007). Indeed, coping theory suggests people draw on different coping strategies depending on the severity of the stressor and how this is appraised (Lazarus and Folkman, 1984). This may better explain seemingly extreme avoidance behaviours identified within the research presented here. Identified moderators that may impede early patient presentation with neutropenic sepsis, include having metastatic disease, being recently bereaved and having fatalistic views about life (which included patients deferring responsibility to God for protection rather than taking responsibility for protecting themselves).

The PCC exchanging information domain may also be extended by findings of the current study and other research (Donovan and Blake, 1992, Thorne, 1999, Rhodes and Cusick, 2000, Wiles and Kinmonth, 2001, Rhodes and Cusick, 2002, Eliasson et al.,2011) by suggesting that some patients may intentionally choose not to adhere with medical advice. Researchers challenge assumptions that non-adherence always results from a lack of clear thinking, beliefs, misunderstandings of information provided or through failed doctor patient communication (Thorne, 1999, Donovan and Blake, 1992). Importantly, clinicians may assume that reporting neutropenic sepsis symptoms is a priority for patients and adherence studies position patients as passive and assume their only option is to comply with medical advice (Donovan and Blake, 1992). Similar findings within qualitative studies of HIV (Rhodes and Cusick, 2000, Rhodes and Cusick, 2002), rheumatology (Donovan and Blake, 1992), myocardial infarction (Wiles and Kinmonth, 2001) and oral chemotherapy (Eliasson, 2011) support the perspective that patients may actively choose not to comply with reporting of neutropenic sepsis. Rheumatology patients were found to consciously weigh up the risks and benefits of actions, and at times chose to alter medication doses or ignore advice. They took the course of action that made most sense to them and fitted in with the constraints of their everyday lives (Donovan and Blake, 1992). Weighing up risks and benefits were also observed in a study where some HIV positive men and their HIV negative partners made conscious decisions not to use condoms during intercourse, even though this represented significant risks to HIV negative partners (Rhodes and Cusick, 2000, Rhodes and Cusick, 2002). Participants valued the loving relationship more than the risk of HIV infection and felt unprotected sex strengthened the relationship and condom use presented a relationship threat through emotional detachment.

A further new finding relevant to exchanging information - and not identified in the PCC model - was that patients apparently took increasing risks (especially those with metastatic disease or who were bereaved) with regard to infection precautions and delaying presenting with symptoms of neutropenic sepsis, as they believed they had “got away” without developing this condition. Similar scenarios are reported within oral chemotherapy and myocardial infarction studies conducted within the UK. An interview study with 21 patients diagnosed with chronic myeloid leukaemia, found intentional non-adherence with oral chemotherapy increased when patients were responding to treatment. This was because patients believed they could afford to miss a few doses (Eliasson, 2011). Furthermore, an interview study conducted with 25 cardiac patients identified that receding feelings of shock following a myocardial infarction reduced motivation to continue with lifestyle changes in the longer term (Wiles and Kinmouth, 2001).

8.2.3 Domain three: Responding to emotions

Patients from this study appeared too anxious to take in information about neutropenic sepsis and avoided engaging with self-management of it. However, clinicians often did not seem to identify or address patients' emotional cues. The responding to emotions domain suggests fears about cancer may negatively impact on successful information delivery. Other studies have reported that patients (Mitchell, 2007, Siminoff and Step, 2005) and carers (Ream et al., 2013a) experience heightened anxiety before chemotherapy. A UK interview study found women with breast cancer (n=12), associated their requiring adjuvant chemotherapy with being seriously ill (Cowley et al., 2000). Furthermore, a UK grounded theory study based on interviews with 27 patients identified a tendency to avoid chemotherapy information that was thought to be confusing or distressing (McCaughan and McKenna, 2007). The current study extends understanding of this to suggest patients' and carers' ability to be attentive to information about neutropenic sepsis may be compromised because this heightens pre-existing fears of dying associated with a life threatening illness and of starting chemotherapy. Moreover, such fears may be exacerbated through frustrated clinicians repeatedly stressing the urgency of calling the hospital with a fever. Clinicians did not explain why a fever was important or explore with patients why they may delay. A similar phenomenon was seen in a non-cancer study where practice nurses persisted with repeated ineffectual didactic information when faced with patient resistance to self-management of chronic diseases (Macdonald et al., 2008).

Patients interviewed in this study dealt with their fears of neutropenic sepsis through avoidance tactics (encompassed within the responding to emotions domain) and normalising tactics (that are not included). Other literature has identified cancer and chemotherapy as threatening patients' normal identity (Van Der Molen, 2000, Farrell et al., 2005, McCaughan and McKenna, 2007). Furthermore, distraction through using avoiding and normalising strategies are common responses to chronic illness (Strauss et al., 1984). This has previously been identified in patients undergoing chemotherapy who strove to maintain normal work, home and social roles (Cowley et al., 2000, Mitchell, 2007). The use of normalisation and avoidance strategies to distract from acknowledging and reporting neutropenic sepsis has not been previously described.

The responding to emotions domain suggests clinicians' illness representations of cancer and associated treatments can differ to those of patients. Illness representations are used by patients to understand and make sense of the cancer experience and are informed by prior experiences, beliefs, others experience, knowledge, psychological status and goals (Epstein and Street, 2007, McCormack et al., 2011). New evidence from the current research identifies that clinicians' view neutropenic sepsis as a life-threatening complication of chemotherapy. However, verbal and written explanations of neutropenic sepsis delivered by clinicians to patients may encourage a view of this as not likely or serious (an infection rather than sepsis). A similar finding, where clinicians' behaviour contributed to patients' misconceptions is described within a grounded theory study to explore patient adherence with oral chemotherapy. Intentional non-adherence appeared to be associated with encouragement by doctors that it was acceptable to miss the odd dose (Eliasson et al., 2011). A further study identified that both verbal and written information provided by clinicians to patients following a myocardial infarction encouraged patients to view it as an acute recoverable event (rather than an indicator of a potentially life-threatening illness). Clinicians apparently framed information about a myocardial infarction in this way because they recognised patients were fearful of dying. However, this approach discouraged patients from making long term lifestyle changes to reduce the chances of further cardiac damage (Wiles and Kinmonth, 2001).

Patients within the current study feared having cancer and starting chemotherapy. Other research supports the emotional impact of cancer diagnoses, reporting that some patients may even be clinically depressed (Farrell et al., 2005, Cancer Research UK 2014, Walker et al., 2014). Estimates of the prevalence of depression in cancer patients across these studies are variable (9.3% - 58%). A small study (Farrell et al., 2005) identified, through psychological screening, that 24% of 33 women undergoing chemotherapy were likely to be anxious or depressed. Cancer Research UK (2014) estimate that up to 58% of patients with cancer in the UK develop depression (Cancer Research UK. 2014. *Cancer incidence statistics : Cancer Research UK*. [ONLINE] Available at: http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/. [Accessed 28 January 2014).

Furthermore, a recent and important study conducted in the UK (Walker et al., 2014) identified the prevalence and treatment of major depression within 21,151 cancer patients. This included 8461 women with breast cancer, 627 (9.3%) (CI 8.7-10.0) of whom were identified, through the study as having a major depression. Importantly, over half of the women with breast cancer who were diagnosed with major depression (429 (68%) had not received treatment for it (Walker et al., 2014).

Poor recognition and treatment of depression by clinicians may be reflective of evidence within the responding to emotions domain, and the findings of this study, that suggest clinicians may miss or ignore emotional cues from patients and focus more on physical aspects of care. Two other studies observed conversations about chemotherapy between doctors and patients (Bakker et al., 2001) and between nurses and patients (Dennison, 1995). These studies reported observation of conversations that appeared controlled by doctors or nurses and were focused on physical chemotherapy symptoms rather than patients' emotional needs. The small UK study (Dennison, 1995) of conversations between eight female patients and eight nurses during administration of first chemotherapy treatments, observed little nurse interaction with patients. Non-technical conversations were superficial; only two nurses explored patients' feelings and understanding about their chemotherapy treatment.

A further cross-sectional study found chemotherapy nurses (n=7) were unable to identify 70% of concerns of 33 women they treated with chemotherapy for breast or gynaecological cancers. Concerns unrecognised by nurses related to chemotherapy side-effects and emotional, relationship and financial worries (Farrell et al, 2005). Similarly, a national UK chemotherapy patient survey of 16,000 patients indicated that few patients were offered opportunities to speak about emotional (62%), psychological (48%), spiritual (32%), or financial (44%) concerns before starting chemotherapy (NHS England, 2013).

Findings presented here and in other studies suggest clinicians do not recognise or respond to emotional cues including signs of depression in women with breast cancer going through chemotherapy (Dennison, 1995, Bakker et al., 2001, Walker et al., 2014). Importantly, a quantitative review and synthesis of 25 studies (Dimatteo et al., 2000) further suggests a significant relationship between depression and non-adherence with treatment (OR of 3.03, 95% CI, 1.96-4.89) for a range of illnesses (including cancer, renal disease and angina).

Consequently, untreated depression may put patients at increased risk of poor adherence with reporting symptoms of neutropenic sepsis.

8.2.4 Domain four: Managing uncertainty

Uncertainty and illness theory (Mishel and Braden, 1988, Mischel, 1990) informs the managing uncertainty domain. Uncertainty is the inability to accurately predict future illness events and outcomes (Mishel and Braden, 1988). The literature review chapter of this thesis (chapter two) identified difficulties in defining neutropenic sepsis. The difference between being neutropenic and having neutropenic sepsis is complex to describe to patients. In addition, there is an issue for clinicians about explaining neutropenic sepsis due to a lack of evidence regarding symptoms to watch out for and how these may vary in different people. This may explain findings presented here - supported by other chemotherapy studies – that patients find chemotherapy side-effect information confusing (Van Der Molen, 2000, Skalla et al., 2004). Regardless, clinicians do not appear to explain to patients what is clearer; the process of neutropenia, the likely timings of it occurring, and that once patients are neutropenic, they have a high risk of developing sepsis.

Research has shown that patients tend to want to understand the treatment plan, likely side effects and how to manage these (Cassileth et al., 1980, Skalla et al., 2004, Kav et al., 2012,) in order to prepare and plan their life during chemotherapy (Ream and Richardson, 1996, Mills and Sullivan, 1999, Skalla et al., 2004, Pedersen et al., 2012). Patients' inability to predict or recognise normal chemotherapy symptoms (termed symptoms profile within illness and uncertainty theory) and to distinguish those that are abnormal (termed event congruence), can cause emotional distress (Mishel and Braden 1988, Pollock et al., 2008) (See Domain three: Responding to emotions). This may further diminish a sense of control (Mishel and Braden, 1988, Mishel, 1990, Stiegelis et al., 2004, Epstein and Street, 2007) and thus the ability to self-care.

Another grounded theory study, of newly diagnosed cancer patients information-seeking behaviours, also found patients often feared going through chemotherapy and held preconceived negative views about this (McCaughan and McKenna, 2007). Uncertainty and illness theory (Mischel and Braden, 1988, Mischel, 1990) further accounts for new findings from this study that suggest patients who are not informed about the reality of chemotherapy side effects may not be attentive to information about neutropenic sepsis, due to a preoccupation with lay perceptions of chemotherapy as toxic and poisonous.

Not knowing the clinical reality is associated with uncertainty and unfounded fears. For some cancer patients not knowing is worse than knowing (Cassileth et al., 1980). Findings presented here suggest uncertainty may encourage avoidance behaviours (See Domain three: Responding to emotions). Importantly, event congruence, defined within illness and uncertainty theory as the consistency between expected and actual chemotherapy symptoms (Mishel and Braden, 1988) were often diametrically opposed. Consequently, patients and carers who developed grade four neutropenic sepsis often found the unexpected and dramatic symptoms of this frightening, a finding also reported by other researchers (Henman et al., 2002, Skalla et al., 2004).

8.2.5 Domain five: Making decisions

Patients may make decisions to have chemotherapy that are not well informed about both benefits and risks. This may subsequently reduce patients' motivation to engage in self-management of chemotherapy, including reporting neutropenic sepsis.

Other researchers have identified patients who were led to believe they could not decline chemotherapy, without compromising their prognosis (Cowley et al., 2000, McCaughan and Thompson, 2000, Henman et al., 2002). The making decisions domain supports findings that patients' willingness to engage with information about neutropenic sepsis may be reduced by the absence of open, honest discussions with clinicians (See Domain three: Fostering healing relationships) about possible benefits and risks of chemotherapy including individual risks of developing neutropenic sepsis. Risk factors for neutropenic sepsis identified within the literature review chapter of this thesis (chapter two), that were present within the research participants, but not referred to by clinicians when communicating with them included: taking chemotherapy drugs with over 20% risk of causing neutropenic sepsis, being aged over 65 years and having advanced disease (Smith et al., 2006, Aapro et al., 2006, Aapro et al., 2011).

The dealing with emotions domain (Epstein and Street, 2007) incorporates clinicians avoiding difficult conversations with patients, because they fear unleashing emotions they might struggle to deal with. However, paternalism through underplaying the seriousness of chemotherapy side effects is apparent within other studies. Twenty of 97 cancer patients, who participated in an American questionnaire study to explore their communication with clinicians, believed information about their diagnosis and treatment were withheld or incomplete (Lerman et al., 1990). Paternalism was also observed through interviews with 12 women with breast cancer whereby clinicians misled them about the seriousness of their condition. Clinicians described adjuvant chemotherapy as an insurance policy rather than discussing patients' prognosis and likely benefits and costs of treatment (Cowley et al., 2000). Furthermore, in a grounded theory study patients (diagnosed with breast (n=26), colon (n=10) and other (n=4) cancers) reported a mismatch between their needs for chemotherapy information and information that was provided to them by clinicians for chances of cure (94.6% versus 34.3%) and effectiveness of chemotherapy in other patients (90% versus 48.5%) (McCaughan and Thompson, 2000). A more recent survey of patients conducted in Ireland (n=473) also suggests that patients do not know about neutropenic sepsis or their personal risk of developing it (Leonard, 2012). Other researchers have identified patients who believe they suffered unnecessary physical harm because they did not have enough information to manage chemotherapy symptoms (Mazor et al., 2012). This highlights not only significant issues for informed consent to chemotherapy but also a power imbalance in favour of clinicians as described by Bakker et al., (2001). They found some women undergoing chemotherapy believed clinicians withheld information so they held the power and control in their relationship.

This literature and the making decisions domain may be informed by new findings that clarify that some clinicians may avoid discussions about neutropenic sepsis because they fear patients refusing chemotherapy if it is fully explained. A possible association is also identified between patients feeling they cannot decline chemotherapy and their unwillingness to engage with self-management of neutropenic sepsis. Importantly, feeling out of control with decisions to treat cancer has also been associated with intentional non-adherence with oral chemotherapy self-medication in women with breast cancer (Atkins and Fallowfield, 2006). Related to this and the domain, is new evidence that poor knowledge of neutropenic sepsis and associated symptoms means patients are unable to make informed decisions about when and how to seek help when it occurs.

8.2.6 Domain six: Enabling self-management

The focus of the PCC 'enabling self-management' domain is on clinicians enabling patients to become active and responsible participants in their health care (Epstein and Street, 2007). This was not achieved for patients within this study, because information provided by clinicians about neutropenic sepsis frightened patients and did not enable or encourage them to take responsibility for it.

The 'enabling self-management' domain draws upon three theories of behaviour change that can be applied to understand why patients may delay presenting to hospital when they develop neutropenic sepsis: 1). The "5A's" (Assess, Advise, Agree, Assist, Arrange) model of behaviour change (Glasgow et al., 2006) will be discussed later in this chapter. Essentially, this aims to help patients develop personal action plans through (a) *assessing* their beliefs and knowledge, (b) *advising* on the risks and benefits of actions, (c) *agreeing* goals, (d) *assisting* in identification of barriers to action and (c) agreeing and *arranging* follow up support. 2). Self-efficacy theory: proposes that an individual's personal motivation to change health behaviours is driven by a belief in their ability to achieve the change. This thereby suggests that people who are led to believe their actions are (or will be) ineffective are likely to avoid the same activity in the future (Bandura, 1988). 3). Self-determination theory: is concerned with a natural inclination towards intrinsically (internally) rather than extrinsically (externally) motivated behaviours (Ryan and Deci, 2000). Core to self-determination theory are three intrinsic patient needs of relatedness (to experience reciprocal caring relationships, usually with clinicians), competence (mastery) and autonomy (to feel in control and responsible for ones' own life). Self-determination theory suggests the presence of relatedness, competence and autonomy are likely to stimulate patients' natural inclination to be self-organised; intrinsic motivation and internalisation of externally motivated behaviours. If innate needs of competence, relatedness and autonomy are not met, the motivation, performance and health of the patient may decline (Ryan and Deci, 2000).

Previous research has not been conducted to explore how effectively patients are equipped to manage reporting of chemotherapy symptoms. Consultations observed during the current study, did not appear to encourage patients to engage in the process and report symptoms of neutropenic sepsis. Witnessed consultations did not seem to meet patients' needs of relatedness, competence or autonomy required to be self-determined (Ryan and Deci, 2000, Deci and Ryan, 2000). Further, clinicians were not observed to promote patient self-efficacy (Bandura, 1988) through instilling mastery and a belief in their ability to manage their chemotherapy side effects at home and to report these appropriately to clinicians. Self-efficacy appeared further compromised after patients felt a bother when they accessed help for chemotherapy symptoms. Patient accounts do suggest that clinicians encourage early patient presentation, through legitimising symptoms of neutropenic sepsis and by taking responsibility for their care.

New findings further suggest patients may struggle to emotionally and physically respond when they develop neutropenic sepsis due to its debilitating nature. This finding is supported by weak evidence described within the literature review chapter of this thesis (chapter two) that suggests grade three and four neutropenia are associated with depression (See Domain three: Responding to emotions) and reduced physical and social functioning (Fortner et al., 2006; Fortner and Houts, 2006). Furthermore, self-efficacy theory suggests a negative stress reaction resulting from a physiological or emotional state is associated with reduced self-efficacy and ability to perform (Bandura, 1988). This has implications for the responsibility then placed upon the carers to make decisions about reacting to getting treatment for neutropenic sepsis. Often carers have only the same - or less - knowledge than the patient about this iatrogenic condition.

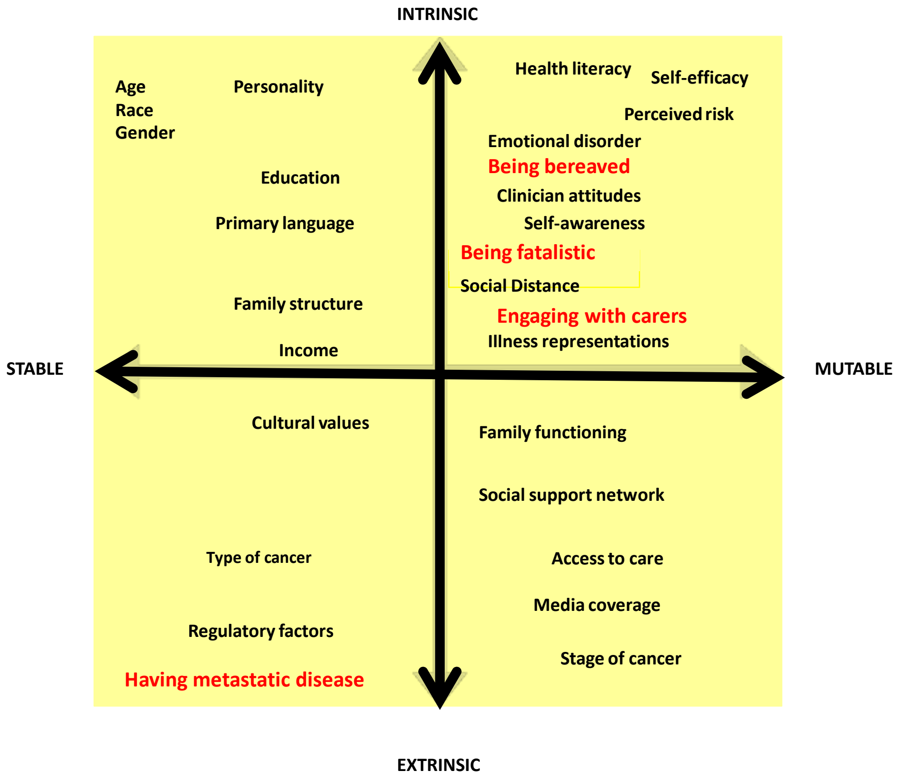
8.2.7 Moderators

Mediating domains for patient-centred communication (Fostering healing relationships; Exchanging information; Responding to emotions; Managing uncertainty; Making decisions and Enabling patient self-management) that impact on patient reporting of neutropenic sepsis have been described. The PCC model also includes factors that moderate relationships between patient-centred communication and the outcome (for the current study the desired outcome is early patient presentation with neutropenic sepsis). The PCC framework includes a two dimensional model (figure 3.3., p70) that presents moderators along the horizontal axis that represent a continuum suggesting the extent to which a moderator is stable (difficult or impossible to change) or mutable (modifiable). The vertical axis represents a continuum between moderators being extrinsic (external) or intrinsic (native/close) to relationships between clinicians, patients and carers. Importantly, moderators on the left hand side of the grid may be less open to change and so may create greater barriers for adherence with reporting of neutropenic sepsis. Moderators on the right hand side may be more malleable through patient-centred communication behaviours.

Findings from this study suggest that some of the mutable moderators included within the PCC model are important to the grounded theory. These include access to care (extrinsic mutable moderator) and clinician attitude (intrinsic mutable moderator). This is because patients who were made to feel they would be a bother for accessing the chemotherapy on-call service were more likely to delay presentation. Further relevant intrinsic mutable moderators that are included within the PCC model are patient and carer perceived risk and illness representation (of neutropenic sepsis which is often minimised to an infection).

Findings from the current study suggest new mutable moderators for adherence with reporting neutropenic sepsis that should be added to PCC model (figure 8.2). These include being recently bereaved, having fatalistic attitudes towards having cancer and engaging with carers (intrinsic mutable moderators that may be malleable through patient-centred communication). Having metastatic disease was further identified as an extrinsic stable moderator. Importantly this suggests patients who have advanced cancer may need additional support to manage and report chemotherapy side effects, including neutropenic sepsis.

Figure 8.2. Updated PCC intrinsic and extrinsic moderating factors - suggested additions in red. (Epstein and Street 2007, p 51). For permission see appendix 2.



8.2.7.1 Having metastatic disease and being bereaved

Findings from this study supports other research that suggests patients with metastatic disease may avoid hearing bad news information about their diagnosis and may be passive during consultations with clinicians (Cassileth et al., 1980, Fallowfield et al., 1995, Butow et al., 1997, Mills and Sullivan, 1999, Pollock et al., 2008). An Australian questionnaire study conducted with 80 cancer patients identified that patients with metastatic disease appeared most passive during consultations with doctors. The researchers suggest this may be due to patients with metastatic disease preferring a paternalistic approach or seeking to avoid negative information (Butow et al, 1997).

Avoidance behaviours during consultations, in people diagnosed with cancer who have also experienced a recent death or imminent death of a friend or family member (bereavement), is a new finding. Research has shown that where people were bereaved and the person that had died was perceived to die 'young' or before their time, or a person experienced multiple bereavements of close family and friends in a short period of time, this could trigger complicated grief reactions (Kissane et al., 1998). This may help to explain the differential findings of those bereaved.

Previous research has shown an association between grief following a bereavement and delayed patient presentation to clinicians with cancer (Zakowski et al., 1997, Lund-Nielsen et al., 2011). A longitudinal study conducted with women undergoing breast screening (Zakowski et al., 1997) reported that a family history of breast cancer was associated with having significantly increased intrusive thoughts. These women appeared less inclined to observe for signs of breast cancer. They also perceived themselves to be at greater risk of developing breast cancer than women with no family history. Importantly, intrusive thoughts, avoidance and perceived risk were exacerbated in women who had experienced death of a parent(s) from cancer (Zakowski et al., 1997). The second interview study, identified reasons that 17 women delayed presenting to clinicians when they developed malignant breast wounds. Delays were sometimes related to grief complicated by beliefs that doctors had been unable to help family members who had died from breast cancer (Lund-Nielsen et al., 2011).

New findings of the current study suggest patients with metastatic disease or who are bereaved may be more fearful of neutropenic sepsis and more likely to adopt avoidance and normalising behaviours than other patients. Importantly, this behaviour may also be linked to increased fears of dying and /or depression. As discussed earlier in this chapter (See Domain three: Responding to emotions) depression in cancer patients often goes untreated (Walker et al., 2014). Depression may further be associated with non-adherence with treatment for cancer (Dimatteo et al., 2000). The possibility of a relationship between depression and/or patients' pessimism about their chances of survival (due to having metastatic disease and being bereaved), and delayed presentation with neutropenic sepsis requires investigation in a future study.

Heightened avoidance behaviours in those with metastatic disease is especially important because high level evidence identified within the literature review chapter (chapter two) suggests they are at increased risk of developing neutropenic sepsis (Smith et al., 2006, Aapro et al., 2011) and of having complications from it (Klastersky et al., 2000). Weaker evidence, also suggests patients with metastatic disease are more likely to present late to hospital when they develop neutropenic sepsis (Malik et al., 2001, Nirenberg et al., 2004). Furthermore, the current study suggests therapeutic relationships with their clinician (See Domain one: Fostering healing relationships) are most valued by patients who have metastatic disease or who are bereaved. These patients also appear more likely to call clinicians they feel connected to when they develop neutropenic sepsis. Importantly, this may cause a delay in treating neutropenic sepsis if the chosen clinician is not immediately available.

8.2.7.2 Engaging with carers

The PCC model includes family functioning and social support networks as intrinsic mutable moderators of patient-centred communication. Findings of this study more specifically suggests that a lack of engagement of carers in the chemotherapy process by patients and /or clinicians reduces the likelihood of patients and carers taking neutropenic sepsis seriously and of promptly reporting symptoms of it to clinicians. A UK study also identified that 37% of 1,700 cancer patients surveyed had not been asked by clinicians about their social support (Macmillan Cancer Support, 2013). Furthermore, other studies have identified cancer (Morris and Thomas, 2001, Northouse et al., 2010, McCarthy, 2011) and chemotherapy (Hilton et al., 2000, Ream et al., 2013b) information delivery to be patient-centred which leaves carers feeling excluded.

Feeling unprepared to care for cancer patients reflects a general concern amongst carers (Morris and Thomas, 2001, Northouse et al., 2010, Macmillan Cancer Support, 2011, Northouse et al., 2012). Furthermore, carers of chemotherapy patients report feeling unable to support patients to recognise and report symptoms of neutropenic sepsis (Royal College of Physicians, 2012, Ream et al., 2013b). An interview study conducted within the UK with 47 patients and 32 carers also identified carers who did not attend chemotherapy information appointments were often unaware of the risk of neutropenic sepsis, symptoms of it or who to call (Morris and Thomas, 2001). Furthermore, a UK, mixed method study where carers completed questionnaires (n=49) and participated in interviews (n=13) identified a lack of knowledge about chemotherapy or who to call for symptom help. This included a case where a patient haemorrhaged at home following chemotherapy (Ream et al 2013a). Importantly, feeling responsible but unprepared to support patients through chemotherapy may heighten carers stress and reduce coping (Mcilfatrick et al., 2006, Northouse et al., 2012, Ream et al., 2013a) and thus possibly their ability to support patients.

Research suggests patients and carers renegotiate their roles during chemotherapy (Mcilfatrick et al 2006; Ream 2013b) and more generally during having cancer (Morris and Thomas, 2001). The concept of family-based care suggests carer roles in chemotherapy side effect management cannot be understood in isolation from roles of patients' (Schumacher et al., 2000). They describe three role scenarios to manage chemotherapy and normal life: patients take the lead; carers take the lead; or roles are divided or more commonly shared (Schumacher et al., 2000, Morris and Thomas, 2001). In the study reported here, women with breast cancer appeared to take the lead in decisions to report neutropenic sepsis. There is though bias inherent with the sample because all patients were female and most carers were their male spouses. Therefore, this only allowed comparison of gender roles between carers who were male partners and female friends, sisters and children.

Little is known about the experience of male partners who do not get involved in chemotherapy care, possibly because they are less accessible to researchers. Nevertheless, gender associated relationships appear important. New findings suggest women may exclude male partners/husbands from the chemotherapy process and request female friends and family members to support them instead. Findings support other research as female friends and family members appear to more easily adopt a caring and emotionally supporting role during chemotherapy than male partners who are perceived as squeamish and unable to cope with seeing their partners receive chemotherapy (Schumacher et al., 2000; Ockerby et al., 2012, Ream et al 2013b).

Other research also identifies female carers who put more pressure on patients to call chemotherapy helplines as neutropenic sepsis symptoms worsen (Schumacher et al., 2000, Morris and Thomas, 2001, Ream et al., 2013b). New findings from the current study, extend this literature to suggest female carers may initially not pressurise patients to call chemotherapy helplines, because they do not recognise neutropenic sepsis symptoms as serious or they seek to avoid frightening patients about the possibility of dying from neutropenic sepsis.

There may also be reasons, other than women preferring the moral support of other women, that male partners do not attend chemotherapy appointments. There is evidence that couples where one has cancer (Northouse et al., 2000, Hilton et al., 2000, Mitchell, 2007) seek to protect each other through withholding emotions. Patients going through chemotherapy have also been found to protect those close to them through hiding emotional distress (Cowley et al., 2000, Pedersen et al., 2012). One mother from this study believed her daughter excluded her male partner because she wanted him to view her as normal, rather than a sick person. Interestingly, a systematic review of the experiences of men in relation to their partners' mastectomy showed they often felt excluded. This was because the women partners did not like them to see their scarred breast or mastectomy site (Rowland and Metcalfe, 2014). A possible reason for sometimes excluding men from providing care was a fear by women, following a mastectomy; of their partner's reactions to their changed or altered breast and that this may change their relationship (Rowland and Metcalfe, 2014).

Male partners may also not attend pre-treatment chemotherapy consultations because of other priorities. Carers from an intervention study reported that family and work commitments reduced their ability to get involved in the chemotherapy process (Ream et al., 2013b). It is possible, that some women prioritise their families support needs over their own during chemotherapy. Childcare may be a priority and financial pressures caused by being unable to work may result in the protection of male partners' jobs. Consequently, childcare or work commitments may reduce male partners' ability to attend chemotherapy consultations, which are usually held during working hours. Whatever the reason for male partners being excluded, this leaves them unaware of the risk of neutropenic sepsis, symptoms or numbers to call and unable to persuade patients to contact the hospital.

8.2.7.3 Being Fatalistic

Development of the grounded theory identified fatalism as an intrinsic mutable moderator to be added to the PCC model. Fatalism is evident in patients with other illnesses. Fatalistic attitudes were noted in some patients following a myocardial infarction, which reduced their inclination to take up healthy lifestyle advice (Wiles and Kinmonth, 2001). Cancer research has also identified an association between fatalistic attitudes and uptake of breast and cervical cancer screening, mainly in African American women. Cancer fatalism is defined across these studies as a pessimistic belief that the presence of cancer means death is inevitable (Skinner et al., 2002, Behbakht et al., 2004, Powe et al, 2006, Cassibba et al., 2013). Research consistently supports findings that ethnicity may be related to fatalism and an associated reduced inclination to undergo cancer screening (Skinner et al., 2002, Behbakht et al., 2004).

Findings of the current study suggest some patients may rely on God to protect them from harm during chemotherapy. Similarly, a questionnaire study conducted with patients (n=105) with a chronic illness or cancer (Cassibba et al., 2013) identified secure attachment to God compared to insecure attachment is associated ($p<.05$) with higher levels of fatalism and lower levels of anxious preoccupation and hopelessness. Secure attachment to God may further lead to passive coping through devolvement of responsibility to God to protect (Cassibba et al., 2013). The role of religion in delayed patient presentation with neutropenic sepsis may be further explained by other literature. This suggests beliefs held by some cancer patients that their destiny is “in the hands of God” may be stronger than their inclination to act. A questionnaire study completed by 146 women with invasive cervical cancer identified that those who relied on their faith to direct health choices avoided knowing about a cancer diagnosis (Behbakht et al., 2004). Furthermore, a questionnaire study with 80 patients identified a significant association between beliefs that God influenced cancer and preferences for less cancer information and detail (Butow et al, 1997). Importantly, a systematic review found evidence that some black African American women believed the outcome of cancer was God’s will, so it was not for them to intervene (Jones et al., 2014). Consequently, it is likely that the knowledge that clinicians would like patients with cancer to know regarding reporting neutropenic sepsis sometimes conflicts with patients’ strong religious beliefs, and it is these latter beliefs that ‘win’.

8.3 Limitations of the study

This study, as with any research, was constrained by a number of factors. Limitations were evident within the following four areas of the research process: sample selection and recruitment, collecting interview data, collecting non-participant observation data and data analysis.

8.3.1 Sample selection and recruitment

The patient sample for this study was confined to women with breast cancer undergoing chemotherapy, so findings may not apply to patients with other cancer diagnoses. Furthermore, there was a confounding variable in that all partners were men, so the only comparison of gender that could be conducted was with friends, children and siblings of the women with cancer. This was also a small study. However, the purpose of grounded theory is not population representativeness, it aims to develop a theory that emerges from the data Therefore, data collection ceased when nothing new emerged to contribute to the developing theory.

Grounded theory directs researchers through constant comparison and theoretical sampling to identify participants likely to be of interest to the emerging theoretical inquiry. Reliance on clinicians to identify and initially approach suitable patients was likely to introduce an element of selection bias. Further, this was not their only priority so recruitment of specific patients of interest sometimes proved difficult and opportunities to include patients with particular characteristics were occasionally missed. In particular, there were difficulties in recruiting patients with metastatic disease, who clinicians may not have wanted to approach to participate in this study. Furthermore, this patient group often appeared to start chemotherapy quickly, which reduced the window of opportunity to obtain informed consent prior to non-participant observation. It was also hoped that patients who had experienced multiple admissions to hospital with neutropenic sepsis may be recruited to establish if behaviour changed over time, as suggested in the data. Unfortunately, such patients could not be identified. It was envisaged male carers, who did not appear aware of neutropenic sepsis or how to act if this occurred, may have been of interest. However, patients who appeared to exclude these male carers from the chemotherapy process also tended not to support their participation in the research.

8.3.2 Collecting interview data

The researcher had limited experience as an interviewer initially, which may have affected the quality of data generated for analysis in the earlier interviews. However, interview and grounded theory training at the start of the research process, along with experience, assisted development of interviewing skills. Interview bias was also likely due to the researcher’s experience as a chemotherapy nurse and in the beginning it was challenging relating to participants as a researcher rather than a nurse. Conversely, bias may have been reduced through reflexivity (detailed later within this chapter) and because the researcher was not known at the research centre so lacked preconceptions about practice there. Prior chemotherapy knowledge also sometimes helped identify phenomena that may be missed by other researchers. An example is an awareness of the likely timing and symptoms of neutropenic sepsis.

Location of interviews differed because participants were offered a choice for these to be conducted either face to face (hospital or home) or via the telephone. A limitation of telephone interviews may have included an inability to witness facial expressions and reactions, although some participants may have felt able to speak more freely over the telephone than through face to face interactions. Most patients and carers chose to be interviewed over the telephone which proved problematic when mobile phone signals were lost or they became distracted so interviews had to be rescheduled. Clinicians were interviewed either over the telephone or face to face and occasionally these interviews were cut short due to clinical commitments, which again may have affected the quality of data collected.

8.3.3 Collecting non-participant observation data

Initially, limited experience as a qualitative researcher may have also affected the quality of non-participant observation data. Through discussion and reflection with supervisors, these skills developed over time and with more experience. Most importantly a limitation of this study element was the potential influence of the presence of the researcher observing patient and clinician behaviours. Clinicians knew the aim of observation was to identify how they communicated with patients and carers about neutropenic sepsis. They may therefore, have stressed the risks of neutropenic sepsis more than usual. This may have been overcome to some extent by not informing clinicians about the purpose of observation; however, a covert approach may have ethically compromised the research and clinician trust in the researcher. Filming consultations may have altered clinicians' usual practice and behaviour in their explanations of neutropenic sepsis. Filming may also have more accurately captured consultation interactions. Clinicians were though used to being observed (e.g. by students) and much less used to having a camera in the room. Furthermore, it may be less intrusive to patients to have another person in the room – a nurse researcher – than to have a video camera. In the event, clinicians, patients and carers appeared to relax into the observations as they became used to these and got to know the researcher.

Witnessed behaviours of observed doctors' consultations matched accounts given by patients and carers during interviews. However, patients indicated chemotherapy nurses did not always present them with information about chemotherapy side effects. Consequently, pre-arranged observation of chemotherapy nurses providing information to specific patients may have not reflected usual practice. Participant observation through working as a chemotherapy nurse or general observation of patient care within the chemotherapy unit may have provided a more in-depth ethnographic account of the culture within which chemotherapy nurses interacted with patients about neutropenic sepsis. However, attention to the grounded theory approach, through ongoing constant comparison between interviews and observation generated a rich descriptive picture of information and support provided to patients about neutropenic sepsis.

8.3.4 Data analysis

Grounded theory suggests only those deeply immersed in collecting data can truly analyse this because it may be misinterpreted by a third party. An additional experienced grounded theory researcher(s), as a collaborative participant in data collection and analysis, may have enabled the grounded theory to develop more quickly and assisted validity. This was not possible due to the research fellowship being undertaken by one researcher. However, grounded theory training, reflecting on the data analysis and discussions with supervisors about possible interpretations (in addition to mentorship by Juliette Corbin, who is an International expert in the grounded theory method) ensured a thorough exploration of the data that was true to the grounded theory method. Analysis was carried out alongside data collection and breaks from this were taken at regular intervals to enable ongoing in-depth analysis. In addition, following the completion of data collection, nine months full-time commitment was dedicated to produce the final analytical description, ensuring this was of high quality. Further, rigour of analysis is demonstrated because the final theory can be applied to each case studied which represents a high quality grounded theory study (Corbin and Strauss 2008).

8.4 Reflexivity within the research process

Constructivist grounded theory requires clarity about the place of the researcher within the research as a reflexive co-constructer of knowledge who puts participants' stories at the heart of the final theoretical interpretation (Charmaz 2006). Reflexive thought included consideration of how my experience as a chemotherapy nurse and other literature impacted on each stage of the research. The intention was to use pre-existing knowledge to inform areas of enquiry and to compare and contrast emerging findings rather than to drive data collection and analysis. However, consideration must be given to how my personal biases and experience may have influenced generation and interpretation of data (Charmaz, 2006). I am a white middle class, British female in my late forties who works as a senior chemotherapy nurse and holds postgraduate qualifications. Balancing my emic or insider perspective as a chemotherapy nurse against an etic perspective as an outside researcher was challenging. I naturally acted and was perceived as a chemotherapy nurse within the research field. Some patients sought my advice about chemotherapy side effects and during one observation I instinctively attended to a patient whom I believed was about to accidently pull out his drip. Clinicians related to me as a chemotherapy nurse which appeared to allow them to speak openly about their experiences. My insider perspective also sometimes got in the way of my seeing the research field with fresh eyes. I, for example, believed I provided good explanations of neutropenic sepsis to patients. I could not understand why they did not act upon my advice to report symptoms of it urgently. I also, as discussed earlier in this chapter, made assumptions that nurses carried out chemotherapy pre-treatment consultations which may have resulted in the process being altered as indicated by Sophia:

"I wonder sometimes whether the effect of you coming in as a researcher when that nurse gave quite a long spiel about it I wondered actually whether it was slightly for your benefit… "

(Sophia)

My background may also have affected my ability to engage with patients and carers from different backgrounds and with different life experiences, about sensitive issues relating to having a life threatening illness. Two examples are provided. Wendy who was older than myself, educated only to secondary school level and had never worked was particularly challenging to interview. Wendy dismissed neutropenic sepsis as unimportant and tended to give short answers to my questions. Wendy had a strong regional accent, and on subsequently listening to her interview recording, I realised she had failed to present to hospital on a previous occasion with apparent symptoms of neutropenic sepsis. On reflection, Wendy may have believed I could not identify with her. Wendy had been reprimanded by other clinicians for not complying with instructions to report neutropenic sepsis symptoms. She may have believed I would also judge her. A similar scenario was observed on reflecting on the interview carried out with Zeena, a Somalian women in her 60's whose husband had been killed in Somalia. Zeena was also educated to secondary school level and English was her second language. The following is an extract from my reflective diary that documented my thoughts following my interview with Zeena:

Reflective diary extract:
I felt like a dog with a bone. Kept asking her the same questions. It was only when I put my questions to one side that I felt we were getting somewhere. She finally came out with the fact her family were trying to persuade her to come to hospital, she didn't want to talk about it.

Zeena came from a different cultural and religious background than myself. Her culture and religious beliefs appeared important to her coping with cancer. She may therefore have not believed I would understand her perspective and might judge her for initially refusing to come to hospital. Had Zeena felt more of an affiliation with myself, she may have been more open to discussing her reactions to having cancer and going through chemotherapy from the start of the interview. Interestingly, I had a more productive interview with Zeena's niece with whom I felt more comfortable talking to. Zeena' niece was younger than myself, born in the UK, educated to postgraduate level and was interested in undertaking nurse training.

I do not have personal experience of a life threatening illness or death. It challenged me to think clinicians might be as equally culpable for patients delayed presentation with neutropenic sepsis as patients were to not reacting to their symptoms. My supervisors and mentor assisted me in understanding that initially I was thinking like a clinician rather than a researcher. I needed 'to get inside the heads of participants' to understand the process from their perspective. As a result, this new insight, understanding and training associated with this doctoral thesis has strengthened my observation and interviewing skills and ability to see the perspective of others.

I also felt more comfortable interacting with other female nurses than doctors which reflects my clinical practice. This is also reflective of the hierarchy inherent in medicine between doctors and nurses due to gender. I consequently found it difficult to challenge doctors' practice and views. Further, a male researcher may have connected with male carers in a different way to myself as a female researcher. A male perspective may have assisted, better understanding of any impact of relationships between couples on reporting of neutropenic sepsis.

The most important element of bias related to me being part of a culture where clinicians did not talk to patients about the risk of death from neutropenic sepsis. Observed explanations of neutropenic sepsis replicated my clinical practice and I was not initially open to the concept that patients were not told about it. I noted in my reflective diary:

Reflective diary extract:
It was beyond me that people did not know about it. I kept making a note of it……when a patient said they weren't told about it I was a bit resistant

I became uncomfortable when I observed Doctor 2 to be more explicit about the risk of death from neutropenic sepsis with Adanna, because I thought he was being too harsh. I became further aware of my discomfort during my MPhil upgrade examination when I expressed a strong resistance to speaking to patients and carers about the risk of death from neutropenic sepsis. I later noted in my reflective diary:

Reflective diary extract:
I didn't want to tell them what it was… I didn't want to talk about the risk of death with patients and carers… I would have got more out of earlier participants if I had felt more comfortable

I feared causing distress and being reprimanded for informing patients they could have died from neutropenic sepsis and on reflection these feelings were related to this being a taboo subject. When I gained the courage to talk about this with patients and carers I preferred to do so via telephone rather than face to face to save embarrassment and remained worried I may have caused upset. I have learnt that patient and carers do not mind having these types of conversations as documented in my reflective diary, following an interview with Zeena:

Reflective diary extract:

I was worried about upsetting her by talking about the fact she could have died, I think this is difficult for me in practice too. I don't know, maybe it wasn't as bad as I thought. I think she liked talking about it

I further understand that beliefs and frustrations I held prior to this research (shared with other clinicians) that I was not getting the message through to patients about the risks of neutropenic sepsis, and an assumption that patients could be persuaded to comply with clinicians' instructions to present early with neutropenic sepsis may have biased the research question:

Why do some patients delay reporting to hospital with signs and symptoms of neutropenic sepsis, and what assists patients to present earlier to reduce the effects of neutropenic sepsis

I have learnt that relationships with clinicians are likely to be core to patients' adherence to advice / instructions from clinicians. Furthermore, people with a life-threatening cancer diagnosis may make informed choices not to adhere with clinical advice to present early with neutropenic sepsis.

Reflexivity ensured transparency of my influence on the research process and identification of researcher bias that importantly included my being part of a culture where the risk of dying from neutropenic sepsis is not spoken about with patients. Further, close supervision and regular breaks from data collection to concentrate on theory development ensured this was generated through robust processes that were true to the constructivist grounded theory method.

8.5 Implications of findings for clinical practice and research

8.5.1 Introduction

A key challenge for clinical practice and future research is to change the interactions where clinicians, patients and carers meet around the issue of neutropenic sepsis. Interactions should move from a subconscious focus on underplaying the seriousness to one that promotes openness and early patient presentation. Implications of findings for clinical practice and research will next be discussed and will draw on four theories incorporated within the PCC model (Epstein and Street, 2007). These are self-efficacy theory (Bandura, 1997), self-determination theory (Ryan and Decci, 2000), the 5A's for patient-centred counselling (Glascow et al., 2003) and Illness and uncertainty theory (Mischell, 1988). These theories (previously described in chapters three and five and summarised in table 8.1) are potentially important to encouraging patients to voluntarily present earlier with neutropenic sepsis or to provide a safety net to capture high risk non-conformists.

8.5.2 Implications for clinical practice

Delayed patient presentation with neutropenic sepsis is a multi-factorial issue that has many implications for practice at organisational and individual, clinician levels. At an organisational level it, is recommended that service models move from target focused, factory systems that process patents through chemotherapy. New, person-centred models should be developed to encourage ongoing, trusting and supportive relationships to develop between clinicians, patients and carers to promote adherence.

Such ambitious system changes may be incorporated within existing chemotherapy services. Remodelling could ensure both treatments are delivered safely and patient supportive care needs are met within existing budgets. Capacity may be released by combining the chemotherapy consent appointment (currently doctor led) with the nurse led pre-treatment consultation. Time spent by nurses to deliver pre-treatment chemotherapy information sessions may also be reduced. A group interactive education session followed by separate personalised consultations may be more effective. A similar approach has been implemented at a UK cancer centre and evaluated through patient surveys (n=56). Findings suggest patients find the group approach supportive and feel less worried about impending chemotherapy (Sullivan et al., 2013). Capacity from chemotherapy nursing roles may further be released through creating less expensive technician roles to support chemotherapy delivery. Time saved through such initiatives may be more effectively used by chemotherapy nurses to interact with patients about their chemotherapy symptoms throughout treatment. Furthermore, junior nurses or even volunteers could be recruited to assist more experienced chemotherapy nurses with proactive monitoring of patients undergoing chemotherapy. Any service change should be piloted and include economic analysis within evaluations.

Investment should also be made in communication skills training for clinicians who interact with patients about chemotherapy. This should replicate qualities of the UK Connected National communication skills training programme (National Cancer Action Team, 2008). This programme is informed by evidence that facilitated experiential learning can enhance and sustain effective clinician communication skills (Maguire et al., 1996, Fallowfield et al., 2003, Wilkinson et al., 2008). This may result in a clinician communication manner that does not encourage patients to feel a bother for reporting chemotherapy side effects. It may also equip clinicians to speak with patients about difficult issues (including the risks of neutropenic sepsis, reasons patients may delay presenting with it and their fears of dying), that if not addressed, may get in the way of early patient presentation with neutropenic sepsis.

Importantly, clinicians need to be shown compassion in order to be compassionate with patients (Youngson, 2011). Research on compassion in nursing (Maben et al., 2007, Maben, 2008, Maben et al., 2010, Maben et al., 2012) offers insight into how this may be achieved through extrinsic motivation including: ensuring clinicians feel valued and listened to, have access to clinical supervision, work within a culture that does not overstretch them, and that values and provides time for compassion. This type of culture may be promoted though application of initiatives encompassing NICE guidance on ‘Promoting Mental Well Being at Work’ (NICE, 2009). This suggests that monitoring and promoting clinicians mental well being enables them to achieve greater job satisfaction (NICE, 2009). Clinicians who feel cared for are more likely to work to their potential, develop positive relationships with others and contribute more to the service (NICE, 2009). Engagement of clinicians in the development of a new person centred chemotherapy service will be core to successful service change and may be achieved by promoting:

> *… a culture of participation, equality and fairness that is based on open communication and inclusion*
>
> (NICE, 2009, p. 8)

Schwartz rounds (Lown and Manning, 2010) may further encourage and sustain compassionate care. Developed in America, Schwartz rounds provide multi-professional forums that facilitate safe discussions about social and emotional issues that arise from clinicians caring for patients. The model was evaluated through surveys of American clinicians who regularly attended these rounds (n=478). The evaluation suggests Schwartz rounds improve team work, reduce clinician perceived distress and increase and sustain their ability to address and deal with patients' psycho-social concerns (Lown and Manning 2010). Schwartz rounds were brought to the UK in 2009, by the King's Fund's Point of Care programme. This included a pilot at two UK hospital trusts that demonstrated a similar positive impact to the US experience (Goodrich, 2012). Schwartz rounds have had rapid uptake within the UK over the last few years and an NIHR funded national evaluation is currently underway (*NIHR Evaluation, Trials and Studies | 13/07/49*. [ONLINE] Available at: http://www.nets.nihr.ac.uk/projects/hsdr/130749. [Accessed 01 November 2014].

Implications for practice at the individual clinician level may be understood within the context of: relationships between clinicians and patients; information exchange; and patients who are at increased risk of delayed presentation. Framing information and promoting self-management are also important to clinical practice and will be discussed later (in this chapter) within recommendations for research. The PCC model and other literature suggests trusting relationships between patients and clinicians that promote continuity of care (i.e. seeing the same clinician more than once), may reduce patient uncertainty and emotional distress, increase coping and control (Sitzia and Wood, 1998, Mills and Sullivan, 1999, Bakker et al., 2001, Epstein and Street, 2007). Continuity of care can also facilitate self-efficacy to perform self-care (Cassileth et al., 1980, Given and Given, 1984). The PCC model suggests a partnership approach between clinicians and patients is likely to encourage patient adherence with reporting of neutropenic sepsis and identify those more likely to delay reporting it (e.g. due to being fatalistic, having metastatic disease or being bereaved). Relationships should encourage exploration of patients' concerns and interactive, tailored information exchange to promote problem focused self-management based on patients agendas, rather than adherence with instructions (Doak et al., 1996, Bakker et al., 2001, McCaughan and McKenna, 2007, Epstein and Street, 2007, Pollock et al., 2008, Kennedy and Lloyd-Williams, 2009, Ormandy, 2011, Kazimierczak et al., 2012). Informed patient decisions to have chemotherapy should be supported by honest discussion about the likely benefits of chemotherapy and risks including neutropenic sepsis. Shared decision making has been shown to increase self-efficacy and subsequent adherence with cancer screening (Manne et al., 2003, Friedman et al., 2004). Furthermore, this may also help clinicians, as they may be less worried about patients refusing treatment if the decision is collaborative.

Patients and carers need guidelines as to the timelines of when patients are most likely to become neutropenic and thereby at risk from sepsis. Research also suggests cancer is an evolving journey and patients become interested in cancer related information when they feel in control (McCaughan and McKenna, 2007), accepting of their diagnosis (Van Der Molen, 2000) and when information about chemotherapy side effects appears personally relevant (Skalla et al., 2004, Pollock et al., 2008). Patients may consequently benefit from hearing about neutropenic sepsis following administration of the first chemotherapy, when initial perceived threats may have subsided and also nearer the time point, when they are at risk of developing neutropenic sepsis. Furthermore, information about chemotherapy should be delivered within a quiet environment rather than busy chemotherapy day units (Treacy and Mayer, 2000). This should enable information exchange between patients and clinicians that is free from distractions.

Clinicians should be aware of patients who may require additional support and monitoring during chemotherapy. Patients who are bereaved or have metastatic disease may be more frightened and resistant to knowing about neutropenic sepsis. Furthermore, some patients maybe more inclined to be fatalistic towards the risks of neutropenic sepsis, which may include reliance on God to protect.

Clinicians should not struggle with providing patients and carers with complex explanations of neutropenic sepsis. Rather, they should focus on encouraging patients and carers to report a fever or chemotherapy symptoms that are different (to their normal symptoms) or that worry them. Importantly, patients should not be advised to wait to feel unwell with a fever of 38^0C or for a rapid deterioration to call chemotherapy help-lines. It may also be important to be honest with patients that the healthcare system is not perfect and so relies on patients to keep oncology clinicians informed if they attend A&E departments.

Illness and uncertainty theory (Mishel and Braden, 1988, Mishel, 1990) stresses the importance of social support to reduce patient uncertainty. Findings of the current study support the concept of family based care (Schumacher et al., 2000, Morris and Thomas, 2001). This suggests clinicians should explore potential family roles for chemotherapy support and capitalise on these through legitimisation, fostering collaborative patterns where carers and patients work together, and through developing targeted interventions for carers. Only one intervention study involved carers who supported patients during chemotherapy (Ream et al., 2013a). Findings of this study identified that a facilitated group education session, DVD and written information reduced unmet need for information and support and increased feelings of legitimisation as carers (Ream et al., 2013a), which can improve the wellbeing of patients and carers (Morris and Thomas, 2001, Northouse et al., 2012).

New findings of this study further suggest women may exclude male partners from their care during chemotherapy. Clinicians should encourage patients to invite partners who live with them or a friend or family member, who they see regularly, to get involved in their care during chemotherapy. This should at least include attendance at chemotherapy pre-treatment consultations, which should be offered at different times (e.g. evenings and weekends) to accommodate carers who work. Clinicians should also assist patients and carers to plan for getting to hospital should the patient become unwell during chemotherapy. The latter may include identifying people who could be on standby to support patients through driving them to hospital or by caring for children if required. Patients could also be advised to have an overnight bag packed. Patients and carers should be forewarned that the patient may feel quite low in mood during an episode of neutropenic sepsis. This may be due to their having cancer and going through chemotherapy or being unwell from symptoms of neutropenic sepsis. It is therefore, imperative that clinicians facilitate carers' authority to intervene and call the helpline on patients' behalf, should patients be unable to judge the seriousness of a neutropenic sepsis episode. It is estimated 23% of cancer patients in the UK do not have support from family and friends (Macmillan Cancer Support, 2011). Consequently, some patients who lack social support or exclude male carers (partners) may require additional support and monitoring from clinicians during chemotherapy.

8.5.3 Recommendations for research

The grounded theory developed through the study outlined within this thesis suggests:

Underplaying the seriousness of neutropenic sepsis is a subconscious collusion between clinicians, patients and carers

Recommendations for future research relate to (1) the design of studies to test and develop the theory further and (2) the development of interventions (to promote early patient presentation with neutropenic sepsis) informed by the grounded theory developed through the current study.

The grounded theory may be applicable to study other high risk conditions where there is a reliance on patients to report symptoms (e.g. acute oncology emergencies such as spinal cord compression) to generate the theory further. Initially, it is recommended the grounded theory is applied to future studies to explore delayed patient presentation with neutropenic sepsis to test its validity. There are also a number of aspects of the theory that may be tested and developed, in relation to observation and through applying the theory to different samples. As identified in the limitations section of this thesis, the design of a future grounded theory study may be improved through filming consultations. Pre-arranged observations of patients' pre-treatment consultations, with chemotherapy nurses also may not have reflected normal practice. A more accurate account may be gained through a general observation of activities within a chemotherapy day unit. This may be achieved through non-participant observation or participant observation through working as a chemotherapy nurse. It is further suggested the grounded theory is tested and developed with patients who have different cancer diagnoses, those receiving different chemotherapy drugs, male patients, children and teenagers, to identify any differences between groups. Patients with more than one admission to hospital with neutropenic sepsis should also be recruited. This may assist in developing a greater insight into changing behaviours or attitudes towards reporting neutropenic sepsis over time.

Patients with fatalistic attitudes towards chemotherapy side effects or who had metastatic disease and / or those who were recently bereaved appeared more likely to take risks in not reporting neutropenic sepsis within this small study. The grounded theory may be further developed through screening patients for depression and by conducting a more in-depth exploration of patients' perceptions and beliefs about their prognosis to validate any relationship between these and reporting of neutropenic sepsis. Furthermore, relationships between patients and their carers during chemotherapy are likely to be complex and may differ dependent on many variables such as age, gender or stability of relationships. Consequently, these variables and reasons patients may exclude carers, or carers cannot get involved in the chemotherapy process should be further explored. Any relationship of gender / relationships that may impact on symptom reporting also warrant further exploration.

Most importantly findings from the current study should inform the design of intervention studies that incorporate a patient self-management approach. Interventions developed through a whole system approach described briefly within the PCC model and applied to chronic disease management (Rogers et al., 2005, Protheroe et al., 2008) may be beneficial. This approach connects patients, clinicians and the healthcare system. It reflects the chronic care model which aims to position self-care within the larger context of professional behaviour change and community engagement. This model refers to whole systems, informing, self-management and engagement and aims for:

> *"informed patients who receive support and guidance from trained practitioners working within a healthcare system geared up to patients' needs"*
>
> (Kennedy et al., 2007, p. 968)

This type of approach would require engagement and participation of chemotherapy nurses. Research suggests a starting point should be exploring further the impact of the chemotherapy environment on nourishing or eroding compassion in chemotherapy nurses towards patients (Maben et al., 2007). Exploration should further identify chemotherapy nurses feelings about engaging with patients' emotional issues, reasons for choosing to work in this field of nursing and the type of service they would like to provide to patients. This may identify potential willingness of nurses to participate in interventions, likely to require closer engagement between themselves and patients to promote earlier reporting of neutropenic sepsis. In addition, any impact of communication skills training, including talking about the risk of death, on clinician engagement with patients about neutropenic sepsis should be evaluated.

New findings of the study presented here suggest patients may avoid hearing about neutropenic sepsis due to fears of having a life threatening illness, starting chemotherapy and the way neutropenic sepsis is presented to them. Importantly, explaining neutropenic sepsis to patients and carers is a problem for clinicians due to a lack of evidence to describe it (see chapter two). A mixed method study (incorporating quantitative and qualitative methods) is recommended, as part of an intervention focused programme of work to generate more accurate and acceptable descriptions of neutropenic sepsis for patients. Symptoms or symptom clusters for neutropenic sepsis may be identified through a quantitative approach. This knowledge should be combined with qualitative data from patients to (1) describe their feelings/experience of having neutropenic sepsis and (2) to identify descriptions of neutropenic sepsis that most effectively communicates the risk, using words that patients and carer understand and find acceptable.

Research suggests that descriptions of symptoms of neutropenic sepsis that are generated by other patients with experience of neutropeinc sepsis may be beneficial. These can promote understanding of an unfamiliar territory through the eyes of someone with shared experiences, perspectives and associated meanings (Mishel and Braden, 1988, McCaughan and McKenna, 2007, Pollock et al., 2008). Patient stories are often the most valued aspect of interventions proven to reduce uncertainty related to chronic disease self-management within primary care (Rogers et al., 2005). In addition, advice from other patients has been described as the most useful source of cancer treatment side effect information (Skalla et al., 2004, Pedersen et al., 2012) and may increase positivity (Cassileth et al., 1980, McCaughan and Thompson, 2000). This approach is termed descriptive norms by NICE (2007); vicarious experiences or modelling within self-efficacy theory (Bandura, 1988) and falls under one of three structure providers described by illness and uncertainty theory (Mishel and Braden 1988).

Interventions generated to include descriptions of neutropenic sepsis that are acceptable to patients, should also seek to address different information seeking behaviours. Application of Miller’s Monitoring and Blunting theory (Miller, 1995) to the study presented here suggests patients apparently coping through monitoring may prefer to be told about the risk of death from neutropenic sepsis and the threat lowered by focusing more on the benefits of acting promptly than the risk of dying. Miller’s theory also indicates those who adopt a blunting coping style should be told in a straightforward, succinct and non-threatening manner what neutropenic sepsis is and the actions they should take (Miller, 1995; Miller, 1998). As highlighted earlier in this chapter, monitoring and blunting theory (Miller, 1995) may be overly simplistic to explain avoidance in patients with cancer and information seeking behaviours may change depending on the perceived threat of a situation (Lazarus and Folkman, 1984). Interventions designed to equip patients to manage reporting of neutropenic sepsis should consequently, be carefully developed and not aimed at all patients independent of their coping style or clinical situation.

Findings of this study suggest self-management interventions may promote patient autonomy to report neutropenic sepsis. Application of the five A's (Assess, Advise, Agree, Assist and Arrange) of Glasgow et al's (2006) "5A's" self-management model suggests clinicians should *'Assess'* patients' concerns (e.g. cancer, chemotherapy, social or work related) and their beliefs and knowledge of neutropenic sepsis. Clinicians should *'Advise'* on the risks of non-adherence and benefits of adherence in reporting neutropenic sepsis. Clinicians should also 'A*gree'* on goals for early presentation and this may be promoted by asking patients to articulate when and how they would access advice for chemotherapy symptoms.

The fourth A *'Assist'* of Glasgow et al's (2006) "5A's"model, is encompassed within NICE guidance for behaviour change (2012) and the Royal College of Physicians report on acute cancer care (2012). This suggests clinicians should *'Assist'* patients to identify potential barriers to early reporting of neutropenic sepsis (e.g. child care or work commitments or difficulty getting to hospital) and develop strategies to overcome them (e.g. galvanising family and friends, or pre-warning work colleagues they may need urgent treatment should they become ill during chemotherapy). Self-management interventions should also '*Assist'* patients to recognise and report neutropenic sepsis. These could be based upon problem solving which can increase patients' self-efficacy with chemotherapy symptom management (Braden et al., 1998, Dodd and Miaskowski, 2000, Given et al., 2004). Symptom triggers focused on the severity of symptoms to report urgently may help patients and carers to identify and report neutropenic sepsis. This would seem like a worthwhile approach. However, this type of intervention must be developed alongside previously mentioned research that is required to identify the relevance of symptoms to neutropenic sepsis. A traffic light system to assist with patient recognition and reporting of urgent (severe) and non urgent chemotherapy symptoms was the most highly patient evaluated aspect of an oral chemotherapy diary developed within the UK (Oakley et al., 2010). Furthermore, patient advice developed by the UK Sepsis Trust highlight the following signs of early sepsis, all of which could be classified as severe symptoms. These symptoms were noticed by patients and carers in this study (although some may be difficult to distinguish from normal chemotherapy side effects) and are highlighted within the literature review chapter of this thesis (chapter two):

- Felt very cold and shivery
- Felt very hot and looked flushed
- Had a high temperature
- Had aching muscles
- Felt very tired
- Have had sickness and/or diarrhoea (upset stomach)
- Not felt like eating
- Seemed confused or drunk, or had slurred speech

(The UK Sepsis Trust 2012, p. 5)

Further, event congruence (consistency between expected and actual events) (Mishel and Braden, 1988) may also be promoted through a UK public health campaign. This has been recommended within a report about unnecessary patient deaths from severe sepsis, including cases of chemotherapy induced neutropenic sepsis (Parliamentary and Health Service Ombudsman, 2013). Such a campaign should be developed and tested in partnership with patients and carers to ensure the message is appropriate and effective. This report highlights the following later symptoms of severe sepsis, which findings from the current study indicate, may heighten fears and avoidance behaviours or encourage patients to ignore earlier symptoms:

- **S**lurred speech
- **E**xtreme muscle pain
- **P**assing no urine
- **S**evere breathlessness
- **I** feel I might die
- **S**kin mottled or discoloured

(Ombudsman 2013, p. 5)

The fifth A (*Arrange)* of Glasgow et al's., (2006) "5 A's" model is associated with the need for relatedness (to experience a reciprocal caring relationship) to be self-determined (to be motivated to draw on intrinsic resources to act in healthy ways). Advocacy incorporates clinicians being available when needed. Findings of this study suggest interventions that incorporate ongoing supportive relationships between clinicians, patients, carers and A&E clinicians should be developed.

Interventions should also evaluate any impact of proactive support in reducing patient delays, associated with uncertainty regarding which chemotherapy symptoms to report. Effectiveness of pro-active care on capturing cases of intentional non-adherence should also be assessed. Intentional, non adherence may be more prevalent in patients who are bereaved or who have metastatic disease (possibly due to pessimism about prognosis); or who are fatalistic about the risks of chemotherapy or lack social support. Two examples of proactive approaches to managing chemotherapy symptoms may be important to future interventions (Molassiotis et al., 2009, Cowie et al., 2013). The first study, evaluated a home chemotherapy nursing intervention to support patient self-management of oral chemotherapy (Molassiotis et al., 2009). Patients in the intervention group (n=83) had fewer chemotherapy symptoms (measured by the National Cancer Institute Common Toxicity Criteria, 1998) than a control group (n=81) and significantly reduced inpatient days (57 versus 167 days). These findings suggest this type of intervention may promote earlier identification and treatment of neutropenic sepsis, and would be cost effective if costs of the intervention are offset by savings made on inpatient bed day usage.

Proactive, interventions are likely to be of most support during the first two chemotherapy treatments as patients become more expert in managing their symptoms after this time (Molassiotis et al., 2009). Consequently, even a home visit or telephone call from a chemotherapy nurse (or a trained and supervised more junior nurse), following the first chemotherapy treatment, may make a difference to early reporting. The intervention could be delivered at day seven, following chemotherapy. At this time patients have experience of other chemotherapy side effects and may be more receptive to hearing about neutropenic sepsis. Day seven following chemotherapy is also close to the risky time for developing neutropenic sepsis.

The second proactive intervention is delivered as part of a programme of research centred upon the Advanced Symptom Management System (ASyMS). This enables patients to input chemotherapy symptoms, including their temperature reading, into a mobile phone (Maguire et al., 2005, Kearney et al., 2006, Maguire et al., 2008, McCall et al., 2008, Gibson et al., 2009, Kearney et al., 2009, McCann et al., 2009, Cowie et al., 2013). Patients next receive electronic symptom management advice or if triggered are connected to a nurse. The nurse follows a symptom management protocol and triages a hospital review if required. Patients reported ASyMs was easy to use (Maguire et al., 2005, McCann et al., 2009) and their confidence in symptom pattern recognition and management improved (Maguire et al., 2005, Kearney et al., 2006). Patients also felt ASyMS improved communication with clinicians (Maguire et al., 2005, Kearney et al., 2006, McCann et al., 2009). Nurses reported that patients beliefs about bothering the helpline were reduced, that serious side effects (including neutropenic sepsis) were identified earlier and hospital admissions were avoided (Kearney et al., 2006, Maguire et al., 2008). An economic evaluation of ASyMS is currently underway, as is the impact on patient reported outcomes including symptom burden and self-efficacy (Cowie et al., 2013). Furthermore, morbidity and mortality data in relation to neutropenic sepsis is being collected through a new European randomised controlled trial through Electronic Symptom Management System Remote Technology (eSMART) (European Commission) [ONLINE] Available at: http://ec.europa.eu/research/health/medical-research/cancer/fp7-projects/esmart_en.html). Accessed 4th October 2014.

As mentioned earlier in this chapter a generic intervention has been developed and tested with carers of patients going through chemotherapy (Ream et al., 2013a). Development of a more tailored intervention for male carers is further recommended. An expressed mantra from male partners from the study reported here was: '*just tell me what to do and I will do it'.* Other research also suggests men need to feel legitimised as carers during chemotherapy and prefer practical roles (Hilton et al., 2000, Ream et al., 2013a). Primary care research has further identified men as preferring a practical approach to their own health (Talley, 2011, Robinson and Robertson, 2013) as demonstrated by a popular practical men's health guide based on the Haynes car manual (Banks, 2002, Banks, 2007, Talley, 2011). Men may, therefore be receptive to interventions based upon clear instructions to equip them to recognise and report neutropenic sepsis. This also fits with task specialisation often adopted during collaborative role patterns (Schumacher et al., 2000).

Finally, enhancing perceptions of control is important to successful behaviour change (NICE, 2007). Results of the study presented here and other research suggests framing messages about neutropenic sepsis to promote self-efficacy (motivation, driven by a belief in ability to act) and response efficacy (belief in effectiveness of taking particular actions) may influence motivation to act (Miller, 1995, NICE, 2007). Findings from this study suggest chemotherapy nurses may not have the skills to empower patients to manage chemotherapy side-effects. Interventions that include motivational interview training for nurses are therefore recommended. Motivational interviewing has been suggested as useful to support self-determination theory interventions to move patients from being passive to being active participants in their healthcare (Vansteenkiste et al., 2012). This is a counselling client-centred approach to motivating behaviour change that does not seek to directly persuade or influence. Rather, this is based on encouraging clients to explore ambivalent feelings and choice about whether to change a behaviour. It has been suggested that self-determination theory provides a theoretical explanation for why motivational interviewing is effective (Vansteenkiste, 2012). Motivational interviewing provides an autonomy stimulating environment so people can draw upon their own motivation and achieve positive outcomes (Markland et al., 2005). Importantly, relatedness may encourage internalisation of externally motivated behaviours when people are not eager to spontaneously engage (Vansteenkiste, 2012), which appeared to be the case for some patients who participated within the study reported here.

Chapter summary:

The study findings and the grounded theory were examined in relation to the PCC model. This identified the PCC model is not only useful in looking at how patients cope with a cancer diagnosis but also how they respond to the risks associated with neutropenic sepsis. Relationships with clinicians (Domain one: Fostering healing relationships) that are built upon trust are important to patients' engagement with reporting of neutropenic sepsis. However, clinicians may avoid emotional interactions with patients (Domain three: Responding to Emotions) and do not fully explain neutropenic sepsis not only due to a lack of evidence (about early symptoms of neutropenic sepsis and how to explain associated risks) but also out of fear patients may refuse treatment (Domain five: Making decisions). Preoccupation with uncertainties (Domain four: Managing uncertainty) about having chemotherapy and overwhelming, confusing and dispassionate information provided by clinicians about neutropenic sepsis (Domain two: Exchanging Information) exacerbates patients' fears of dying and encourages avoidance behaviours. Patients are not equipped to be responsible for reporting symptoms of neutropenic sepsis (Domain six: Enabling Self-management). Uncertainty (Domain four: Managing uncertainty) about symptoms of neutropenic sepsis affects patients willingness and ability to engage with reporting of it. Furthermore, patients may be put off from calling chemotherapy helplines by busy technically focused clinicians and may delay contact in order to speak to clinicians who they feel connected to (Domain one: Fostering healing relationships).

Patients may be motivated to report neutropenic sepsis through relationships with clinicians that encourage emotional engagement, openness, ongoing information exchange and support, shared goal setting and shared decision making. Accurate messages about the risks of neutropenic sepsis framed to increase self-efficacy and response efficacy through understanding the benefits of early reporting may reduce delays. Variations within the process relate to newly identified mutable moderators that are: being fatalistic towards having cancer, being bereaved and not engaging with carers and a stable moderator that is having metastatic disease. The extended PCC model now requires testing through further research to explore delayed reporting of neutropenic sepsis and patient responses to other oncology emergencies to validate and further refine it. It is also recommended the findings of this grounded theory study inform the development of interventions to assist patients, carers and clinicians to facilitate earlier identification and treatment of neutropenic sepsis.

Limitations of the study include findings that may not be applicable beyond patients who have a breast cancer diagnosis and may under represent those with advanced cancer. Furthermore, the impact of gender and relationships between patients and carers on reporting of neutropenic sepsis require further exploration. Researcher' presence may have affected participants' behaviour, areas of inquiry pursued and interpretation of findings and analysis to develop the grounded theory. However, reflexivity, supervision and close attention to the grounded theory method enabled researcher influence to be managed and accounted for throughout the research process.

8.6 In conclusion

Diligent attention to the constructivist grounded theory approach and application of the Patient-centred Cancer Communication Model (Epstein and Street, 2007) and other literature to inform, rather than drive, data analysis and interpretation enabled development of a unique theory grounded in the data. This suggests patients may delay presenting to hospital when they develop neutropenic sepsis due to a subconscious collusion between clinicians, patients and carers that underplays the seriousness of it. Importantly, the research process enabled a deep understanding of the dread and fear experienced by patients starting chemotherapy. Fears include having a life threatening illness and potential death from neutropenic sepsis. This often left patients and carers not wanting or being able to hear about neutropenic sepsis. Processing patients through a system that relies on them to recognise and report neutropenic sepsis symptoms, that clinicians cannot describe, may discourage early presentation to hospital. Indications that patients feel a bother for reporting neutropenic sepsis symptoms, further suggests patients may suffer unnecessarily with other chemotherapy side effects that go unreported.

Findings from this study suggest a need to step back and review chemotherapy services with fresh eyes and remodel these to incorporate ongoing, supportive relationships that enable open discussions between clinicians and patients about the potential benefits and risks of chemotherapy, including neutropenic sepsis. New models of care should equip and support patients and carers to manage chemotherapy side effects at home. Importantly, these should be informed by research to identify descriptions of neutropenic sepsis that patients understand and enable early recognition of it. A review of the literature suggests results from this study have International implications for chemotherapy services. It is consequently hoped these will inform further research and changes in practice to enable better chemotherapy symptom management and earlier treatment of life threatening chemotherapy side effects including neutropenic sepsis.

References

References

Aapro, M. S., Bohlius, J., Cameron, D. A., Lago, L. D., Donnelly, J. P., Kearney, N., Lyman, G. H., Pettengell, R., Tjan-Heijnen, V. C., Walewski, J., Weber, D. C. & Zielinski, C. 2011. 2010 update of EORTC guidelines for the use of granulocyte-colony stimulating factor to reduce the incidence of chemotherapy-induced febrile neutropenia in adult patients with lymphoproliferative disorders and solid tumours. *European Journal of Cancer,* 47**,** 8-32.

Aapro, M. S., Cameron, D. A., Pettengell, R., Bohlius, J., Crawford, J., Ellis, M., Kearney, N., Lyman, G. H., Tjan-Heijnen, V. C., Walewski, J., Weber, D. C. & Zielinski, C. 2006. EORTC guidelines for the use of granulocyte-colony stimulating factor to reduce the incidence of chemotherapy-induced febrile neutropenia in adult patients with lymphomas and solid tumours. *European Journal of Cancer,* 42**,** 2433-2453.

Andreassen, S., Randers, I., Näslund, E., Stockeld, D. & Mattiasson, A.-C. 2005. Family members' experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer. *European Journal of Cancer Care,* 14**,** 426-434.

Arksey, H. & O'malley, L. 2005. Scoping studies: towards a methodological framework. *International journal of social research methodology,* 8**,** 19-32.

Arora, N. K. 2003. Interacting with cancer patients: the significance of physicians' communication behavior. *Social Science & Medicine,* 57**,** 791-806.

Atkins, L. & Fallowfield, L. 2006. Intentional and non-intentional non-adherence to medication amongst breast cancer patients. *European Journal of Cancer,* 42**,** 2271-2276.

Bakker, D. A., Fitch, M. I., Gray, R., Reed, E. & Bennett, J. 2001. Patient–health care provider communication during chemotherapy treatment: the perspectives of women with breast cancer. *Patient Education and Counseling,* 43**,** 61-71.

Bandura, A. 1977. Self-efficacy: toward a unifying theory of behavioral change. *Psychological review,* 84**,** 191.

Bandura, A. 1988. Self-efficacy conception of anxiety. *Anxiety Research,* 1**,** 77-98.

Bandura, A. 1994. *Self-efficacy*, Wiley Online Library.

Banks, I. 2002. *Man Manual,* Yeovil, UK, Haynes.

Banks, I. 2007. *Man Manual 2nd ed.,* Yeovil, UK, Haynes.

Behbakht, K., Lynch, A., Teal, S., Degeest, K. & Massad, S. 2004. Social and cultural barriers to Papanicolaou test screening in an urban population. *Obstet Gynecol,* 104**,** 1355-61.

Bernard, G. R., Vincent, J.-L., Laterre, P.-F., Larosa, S. P., Dhainaut, J.-F., Lopez-Rodriguez, A., Steingrub, J. S., Garber, G. E., Helterbrand, J. D., Ely, E. W. & Fisher, C. J. 2001. Efficacy and Safety of Recombinant Human Activated Protein C for Severe Sepsis. *New England Journal of Medicine,* 344**,** 699-709.

Blumer, H. 1969. Symbolic Interactionism; Perspective and Method. Englewood Cliffs, NJ: Prentice-Hall.

Brewer, J. D. 2000. Ethnography. Buckingham. Open University Press.

Butow, P., Maclean, M., Dunn, S., Tattersall, M. & Boyer, M. 1997. The dynamics of change: cancer patients' preferences for information, involvement and support. *Annals of Oncology,* 8**,** 857-863.

Cancer Research UK. *About depression and cancer: Cancer Research UK.* *http://www.cancerresearchuk.org/cancer-help/coping-with-cancer/coping-emotionally/cancer-and-your-emotions/sadness-and-depression/about-depression-and-cancer* [Online]. [Accessed 23.10.13].

Cancer Research UK. *Cancer incidence statistics:* Cancer Research UK.*http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/* [Online]. [Accessed 28.01.14].

Cassibba, R., Papagna, S., Calabrese, M. T., Costantino, E., Paterno, A. & Granqvist, P. 2013. The role of attachment to God in secular and religious/spiritual ways of coping with a serious disease. *Mental Health, Religion & Culture*, 1-10.

Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K. & March, V. 1980. Information and participation preferences among cancer patients. *Annals of internal medicine,* 92, 832-836.

Charmaz, K. 2006. *Constructing Grounded Theory,* London, SAGE Publications.

Charmaz, K. & Mitchell, R. G. 2000. Grounded Theory: Objectivist and Constructivist Methods *In:* Denzin, N. & Lincoln, Y. (eds.) *In Handbook of Qualitative Research.* Thousand Oaks, CA: Sage.

Charmaz, K. & Mitchell, R. G. 2001. Grounded theory in ethnography. *In:* Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds.) *In Handbook of ethnography.* London: Sage.

Chirivella, I., Bermejo, B., Insa, A., Pérez-Fidalgo, A., Magro, A., Rosello, S., García-Garre, E., Martín, P., Bosch, A. & Lluch, A. 2009. Optimal delivery of anthracycline-based chemotherapy in the adjuvant setting improves outcome of breast cancer patients. *Breast Cancer Research and Treatment,* 114, 479-484.

Cohen, F. & Lazarus, R. S. 1973. Active coping processes, coping dispositions, and recovery from surgery. *Psychosomatic Medicine,* 35, 375-389.

Corbin, J. & Strauss, A. 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory,* London, Sage Publications Ltd.

Cowie, J., Mccann, L., Maguire, R., Kearney, N., Connaghan, J., Paterson, C., Hughes, J. & Di Domenico, D. 2013. Real-time management of chemotherapy toxicity using the Advanced Symptom Management System (ASyMS). *Journal of Decision Systems,* 22, 43-52.

Cowley, L., Heyman, B., Stanton, M. & Milner, S. J. 2000. How women receiving adjuvant chemotherapy for breast cancer cope with their treatment: a risk management perspective. *Journal of Advanced Nursing,* 31, 314-321.

Critical Appraisal Skills Programme (CASP) - Qualitative Research Checklist. 2014 Critical Appraisal Skills Programme (CASP). 2014. CASP Checklists (http://www.casp-uk.net/#!casp-tools-checklists/c18f8). Oxford.

Dancey, J. T., Deubelbeiss, K. A., Harker, L. A. & Finch, C. A. 1976. Neutrophil kinetics in man. *J Clin Invest,* 58, 705-15.

Deci, E. L. 1975. *Intrinsic motivation,* New York, Plenum.

Deci, E. L. & Ryan, R. M. 1985. *Intrinsic Motivation and Self-Determination in Human Behavior,* New York, Plenum.

Deci, E. L. & Ryan, R. M. 2000. The" what" and" why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological inquiry,* 11, 227-268.

Dellinger, R. P., Levy, M. M., Rhodes, A., Annane, D., Gerlach, H., Opal, S. M., Sevransky, J. E., Sprung, C. L., Douglas, I. S., Jaeschke, R., Osborn, T. M., Nunnally, M. E., Townsend, S. R., Reinhart, K., Kleinpell, R. M., Angus, D. C., Deutschman, C. S., Machado, F. R., Rubenfeld, G. D., Webb, S. A., Beale, R. J., Vincent, J. L., Moreno, R. & Surviving Sepsis Campaign Guidelines Committee Including the Pediatric Subgroup 2013. Surviving sepsis campaign: international guidelines for management of severe sepsis and septic shock: 2012. *Crit Care Med,* 41, 580-637.

Dennison, S. 1995. An exploration of the communication that takes place between nurses and patients whilst cancer chemotherapy is administered. *Journal of Clinical Nursing,* 4, 227-233.

Denzin, N. K. & Lincoln, Y. S. 2005. *The Sage Handbook of Qualitative Research,* London, Sage Publications Ltd.

Dimatteo, M. R., Lepper, H. S. & Croghan, T. W. 2000. Depression is a risk factor for noncompliance with medical treatmentmeta-analysis of the effects of anxiety and depression on patient adherence. *Archives of internal medicine,* 160, 2101-2107.

Doak, L. G., Doak, C. C. & Meade, C. D. Year. Strategies to improve cancer education materials. *In:* Oncology Nursing Forum, 1996. 1305-1312.

Dodd, M. & Mood, D. 1981. Chemotherapy: helping patients to know the drugs they are receiving and their possible side effects. *Cancer nursing,* 4**,** 311.

Dodd, M. J. & Ahmed, N. 1987. Preference for type of information in cancer patients receiving radiation therapy. *Cancer nursing,* 10**,** 244-251.

Dodd, M. J. & Miaskowski, C. Year. The PRO-SELF Program: a self-care intervention program for patients receiving cancer treatment. *In:* Seminars in oncology nursing, 2000. Elsevier, 300-308.

Donovan, J. L. & Blake, D. R. 1992. Patient non-compliance: deviance or reasoned decision-making? *Social Science & Medicine,* 34**,** 507-513.

Dubois, S. & Loiselle, C. G. 2009. Cancer informational support and health care service use among individuals newly diagnosed: a mixed methods approach. *Journal of evaluation in clinical practice,* 15**,** 346-359.

Dunn, S. M., Patterson, P. U., Butow, P. N., Smartt, H. H., Mccarthy, W. H. & Tattersall, M. 1993. Cancer by another name: a randomized trial of the effects of euphemism and uncertainty in communicating with cancer patients. *Journal of Clinical Oncology,* 11**,** 989-996.

Eliasson, L., Clifford, S., Barber, N. & Marin, D. 2011. Exploring chronic myeloid leukemia patients' reasons for not adhering to the oral anticancer drug imatinib as prescribed. *Leukemia Research,* 35**,** 626-630.

Electronic Symptom Management System Remote Technology (eSMART). European Commission. Accessed on line 04.10.14 http://ec.europa.eu/research/health/medical-research/cancer/fp7-projects/esmart_en.html

Epstein, R. & Street, R. L. 2007. *Patient-centered communication in cancer care: promoting healing and reducing suffering*, National Cancer Institute, US Department of Health and Human Services, National Institutes of Health.

Fallowfield, L., Ford, S. & Lewis, S. 1995. No news is not good news: information preferences of patients with cancer. *Psycho-Oncology,* 4**,** 197-202.

Fallowfield, L., Heaven, C., Patceathly, C., Ramirez, A., Roberts, A. & Wilkinson, S. 2006. Connected, National Communication Skills Training, Participant Handbook, Advanced Communication Skills. London: National Cancer Action Team.

Fallowfield, L., Jenkins, V., Farewell, V. & Solis-Trapala, I. 2003. Enduring impact of communication skills training: results of a 12-month follow-up. *British Journal of Cancer,* 20;89(8):1445-9

Farrell, C., Heaven, C., Beaver, K. & Maguire, P. 2005. Identifying the concerns of women undergoing chemotherapy. *Patient Education and Counseling,* 56**,** 72-77.

Fortner, B., Schwartzberg, L., Tauer, K., Houts, A., Hackett, J. & Stolshek, B. 2005a. Impact of chemotherapy-induced neutropenia on quality of life: a prospective pilot investigation. *Supportive Care in Cancer,* 13**,** 522-528.

Fortner, B. V., Tauer, K. W., Okon, T., Houts, A. C. & Schwartzberg, L. S. 2005b. Experiencing neutropenia: Quality of life interviews with adult cancer patients. *BMC Nursing,* 4**,** 4-12.

Fortner, B. V. & Houts, A. C. 2006. Greater Physical and Psychological Symptom Burden in Patients with Grade 3/4 Chemotherapy-Induced Neutropenia. *Supportive Cancer Therapy,* 3**,** 173-177.

Fortner, B. V., Houts, A. C. & Schwartzberg, L. S. 2006. A prospective investigation of chemotherapy-induced neutropenia and quality of life. *Journal of Supportive Oncology,* 4**,** 472-8.

Francis, R. 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary. TSO Shop.

Friedman, L. C., Webb, J. A. & Everett, T. E. 2004. Psychosocial and Medical Predictors of Colorectal Cancer Screening Among Low-Income Medical Outpatients. *Journal of Cancer Education,* 19**,** 180-186.

Gibson, F., Aldiss, S., Taylor, R. M., Maguire, R. & Kearney, N. 2009. Involving health professionals in the development of an advanced symptom management system for young people: The ASyMS©-YG study. *European Journal of Oncology Nursing,* 13**,** 187-192.

Given, B. A. & Given, C. W. 1984. Creating a climate for compliance. *Cancer nursing,* 7**,** 139-148.

Given, C., Given, B., Rahbar, M., Jeon, S., Mccorkle, R., Cimprich, B., Galecki, A., Kozachik, S., Brady, A. & Fisher-Malloy, M. J. 2004. Effect of a cognitive behavioral intervention on reducing symptom severity during chemotherapy. *Journal of Clinical Oncology,* 22**,** 507-516.

Glaser, B. G. & Strauss, A. L. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research,* Chicago, Aldine Publishing Company.

Glaser, B. G. 1978. *Theoretical sensitivity: Advances in the methodology of grounded theory,* Mill Valley, CA, Sociology press.

Glaser, B. G. 1992. *Basics of Grounded Theory Analysis: Emergence Vs. Forcing,* California, Sociology Press.

Glasgow, R. E., Davis, C. L., Funnell, M. M. & Beck, A. 2003. Implementing practical interventions to support chronic illness self-management. *Joint Commission Journal on Quality and Patient Safety,* 29**,** 563-574.

Glasgow, R. E., Emont, S. & Miller, D. C. 2006. Assessing delivery of the five 'As' for patient-centered counseling. *Health Promotion International,* 21**,** 245-255.

Goodrich, J. 2012. Supporting hospital staff to provide compassionate care: Do Schwartz Center Rounds work in English hospitals? J*ournal of the Royal Society of Medicine* 105, 117-122.

Gough, D., Thomas, J. & Oliver, S. 2012. Clarifying differences between review designs and methods. *Syst Rev,* 1**,** 28.

Green, J. & Thorogood, N. 2004. *Qualitative methods for health research,* London, Sage Publication Ltd.

Griffiths, P., Bennett, J. & Smith, E. 2009. The size, extent and nature of the learning disability nursing research base: a systematic scoping review. *International Journal of Nursing Studies,* 46(4), 490–507.

Hammersley, M. & Atkinson, P. 2007. *Ethnography: Principles in practice,* Third Edition. London, Routledge.

Harris, D. M., Miller, J. E. & Davis, D. M. 2003. Racial differences in breast cancer screening, knowledge and compliance. *J Natl Med Assoc,* 95**,** 693-701.

Henman, M., Butow, P., Boyle, F. & Tattersall, M. 2002. Lay constructions of decision-making in cancer. *Psycho-Oncology,* 11**,** 295-306.

Higgins, A. 2008. Raising awareness of neutropenic sepsis risk in ambulatory patients. *Cancer Nursing Practice,* 7**,** 34-38.

Higgins, A. & Hill, A. 2012. Effectiveness of a neutropenic sepsis clinical pathway. *Cancer Nursing Practice,* 11**,** 22-27.

Hilton, B. A., Crawford, J. A. & Tarko, M. A. 2000. Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. *Western journal of nursing research,* 22**,** 438-459.

Jones, C. E., Maben, J., Jack, R. H., Davies, E. A., Forbes, L. J., Lucas, G. & Ream, E. 2014. A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. *BMJ Open,* 4.

Kav, S., Tokdemir, G., Reyhan Tasdemir, A. Y. & Dinc, D. 2012. Patients with Cancer and their Relatives Beliefs, Information Needs and Information-Seeking Behavior about Cancer and Treatment. *Asian Pacific Journal of Cancer Prevention,* 13**,** 6027-6032.

Kazimierczak, K. A., Skea, Z. C., Dixon-Woods, M., Entwistle, V. A., Feldman-Stewart, D., N'dow, J. M. & Maclennan, S. J. 2012. Provision of cancer information as a “support for navigating the knowledge landscape”: Findings from a critical interpretive literature synthesis. *European Journal of Oncology Nursing*.

Kearney, N., Kidd, L., Miller, M., Sage, M., Khorrami, J., Mcgee, M., Cassidy, J., Niven, K. & Gray, P. 2006. Utilising handheld computers to monitor and support patients receiving chemotherapy: results of a UK-based feasibility study. *Supportive Care in Cancer,* 14**,** 742-752.

Kearney, N., Mccann, L., Norrie, J., Taylor, L., Gray, P., Mcgee-Lennon, M., Sage, M., Miller, M. & Maguire, R. 2009. Evaluation of a mobile phone-based, advanced symptom management system (ASyMS©) in the management of chemotherapy-related toxicity. *Supportive Care in Cancer,* 17**,** 437-444.

Kennedy, A., Rogers, A. & Bower, P. 2007. Support for self care for patients with chronic disease. *BMJ*, 335, 968-970.

Kennedy, V. L. & Lloyd-Williams, M. 2009. Information and communication when a parent has advanced cancer. *Journal of affective disorders,* 114**,** 149-155.

Kinmonth, A. L., Woodcock, A., Griffin, S., Spiegal, N. & Campbell, M. J. 1998. Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. *BMJ: British Medical Journal,* 317**,** 1202.

Kissane, D. W., Bloch, S., Mckenzie, M., Mcdowall, A. C. & Nitzan, R. 1998. Family grief therapy: A preliminary account of a new model to promote healthy family functioning during palliative care and bereavement. *Psycho-Oncology,* 7**,** 14-25.

Klastersky, J., Paesmans, M., Rubenstein, E. B., Boyer, M., Elting, L., Feld, R., Gallagher, J., Herrstedt, J., Rapoport, B., Rolston, K., Talcott, J. & For the Study Section on Infections of Multinational Association for Supportive Care in Cancer 2000. The Multinational Association for Supportive Care in Cancer Risk Index: A Multinational Scoring System for Identifying Low-Risk Febrile Neutropenic Cancer Patients. *Journal of Clinical Oncology,* 18**,** 3038-3051.

Kuderer, N. M., Dale, D. C., Crawford, J., Cosler, L. E. & Lyman, G. H. 2006. Mortality, morbidity, and cost associated with febrile neutropenia in adult cancer patients. *Cancer,* 106**,** 2258-2266.

Kumar, A., Roberts, D., Wood, K. E., Light, B., Parrillo, J. E., Sharma, S., Suppes, R., Feinstein, D., Zanotti, S., Taiberg, L., Gurka, D. & Cheang, M. 2006. Duration of hypotension before initiation of effective antimicrobial therapy is the critical determinant of survival in human septic shock. *Crit Care Med,* 34**,** 1589-96.

Kurtz, M. E., Kurtz, J., Given, C. W. & Given, B. 2006. Effects of a symptom control intervention on utilization of health care services among cancer patients. *Medical science monitor: international medical journal of experimental and clinical research,* 12**,** CR319.

Law, M., Stewart, D., Pollock, N., Letts, L., Bosch, J. &Westmorland M. 1998. Critical Review Form, McMaster University http://www.srs-mcmaster.ca/Portals/20/pdf/ebp/quanreview_form1.doc

Lazarus, R. & Folkman, S. 1984. *Stress, appraisal and coping,* New York, NY, Springer Publishing Company.

Lazarus, R. S. 1966. *Psychological stress and the coping process,* New York, NY, McGraw-Hill.

Leonard, K. 2012. A European survey relating to cancer therapy and neutropenic infections: Nurse and patient viewpoints. *European Journal of Oncology Nursing,* 16**,** 380-386.

Lerman, C., Rimer, B., Blumberg, B., Cristinzio, S., Engstrom, P. F., Macelwee, N., O'Connor, K. & Seay, J. 1990. Effects of coping style and relaxation on cancer chemotherapy side effects and emotional responses. *Cancer nursing,* 13**,** 308-315.

Lown, B. A., & Manning, F. 2010. The Schwartz Center Rounds: evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Academic Medicine,* 85(6), 1073-81.

Lund-Nielsen, B., Midtgaard, J., Rørth, M., Gottrup, F. & Adamsen, L. 2011. An Avalanche of Ignoring-A Qualitative Study of Health Care Avoidance in Women With Malignant Breast Cancer Wounds. *Cancer nursing,* 34**,** 277-285 10.1097/NCC.0b013e3182025020.

Maben, J., Latter, S. & Clark, J. M. 2007. The sustainability of ideals, values and the nursing mandate: evidence from a longitudinal qualitative study. *Nursing Inquiry,* 14**,** 99-113.

Maben, J. 2008. Employee engagement and retention in the nursing workforce: A case study of an inner-London acute trust. *Final Report.*

Maben, J., Cornwell, J. & Sweeney, K. 2010. In praise of compassion. *Journal of Research in Nursing,* 37**,** 9.

Maben, J., Adams, M., Peccei, R., Murrells, T. & Robert, G. 2012. 'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care. *International Journal of Older People Nursing,* 7**,** 83-94.

Macdonald, W., Rogers, A., Blakeman, T. & Bower, P. 2008. Practice nurses and the facilitation of self-management in primary care. *Journal of Advanced Nursing,* 62**,** 191-199.

Macmillan Cancer Support. http://www.macmillan.org.uk/ [Online].

Macmillan Cancer Support. 2011. More Than a Million; Understanding the UK carers of people with cancer – a report by Ipsos Mori for Macmillan Cancer Support

Macmillan Cancer Support. 2013. Facing the fight alone, Isolation among cancer patients.

Maguire, P., Booth, K., Elliott, C. & Jones B. 1996. Helping health professionals involved in cancer care acquire key interviewing skills – the impact of workshops. E*uropean Journal of Cancer*, 32A(9), 1486-1489.

Maguire, R., Mccann, L., Miller, M. & Kearney, N. 2008. Nurse's perceptions and experiences of using of a mobile-phone-based Advanced Symptom Management System (ASyMS©) to monitor and manage chemotherapy-related toxicity. *European Journal of Oncology Nursing,* 12**,** 380-386.

Maguire, R., Miller, M., Sage, M., Norrie, J., Mccann, L., Taylor, L. & Kearney, N. 2005. Results of a UK based pilot study of a mobile phone based advanced symptom management system (ASyMS) in the remote monitoring of chemotherapy related toxicity. *Clinical Effectiveness in Nursing,* 9**,** 202-210.

Malik, I., Hussain, M. & Yousuf, H. 2001. Clinical Characteristics and Therapeutic Outcome of Patients with Febrile Neutropenia who Present in Shock: Need for Better Strategies. *Journal of Infection,* 42**,** 120-125.

Manne, S., Markowitz, A., Winawer, S., Guillem, J., Meropol, N. J., Haller, D., Jandorf, L., Rakowski, W., Babb, J. & Duncan, T. 2003. Understanding Intention to Undergo Colonoscopy among Intermediate-Risk Siblings of Colorectal Cancer Patients: A Test of a Mediational Model. *Preventive Medicine,* 36**,** 71-84.

Markland, D., Ryan, R. M., Tobin, V. J. & Rollnick, S. 2005. Motivational interviewing and self–determination theory. *Journal of social and clinical psychology,* 24**,** 811-831.

Marks, D. F. & Evans, B. 2005. *Health psychology: Theory, research and practice,* London, Sage Publications.

Mazor, K. M., Roblin, D. W., Greene, S. M., Lemay, C. A., Firneno, C. L., Calvi, J., Prouty, C. D., Horner, K. & Gallagher, T. H. 2012. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *Journal of Clinical Oncology,* 30**,** 1784-1790.

Mccall, K., Johnston, B., Mccann, L., Keen, J., Farrer, K. & Maguire, R. 2008. Perceptions of the use of a remote monitoring system in patients receiving palliative care at home. *International journal of palliative nursing,* 14**,** 426-431.

Mccann, L., Maguire, R., Miller, M. & Kearney, N. 2009. Patients' perceptions and experiences of using a mobile phone-based advanced symptom management system (ASyMS©) to monitor and manage chemotherapy related toxicity. *European Journal of Cancer Care,* 18**,** 156-164.

Mccarthy, B. 2011. Family members of patients with cancer: What they know, how they know and what they want to know. *European Journal of Oncology Nursing,* 15**,** 428-441.

Mccaughan, E. & Mckenna, H. 2007. Never-ending making sense: towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients. *Journal of Clinical Nursing,* 16**,** 2096-2104.

Mccaughan, E. M. & Thompson, K. A. 2000. Information needs of cancer patients receiving chemotherapy at a day-case unit in Northern Ireland. *Journal of Clinical Nursing,* 9**,** 851-858.

Mccorkle, R. & Ehlke, G. Year. Both sides of the fence: A nurse's personal experience with cancer and her rehabilitation needs. *In:* 7th International Conference on Cancer Nursing, Vienna, 1992. 15-16.

Mccormack, L. A., Treiman, K., Rupert, D., Williams-Piehota, P., Nadler, E., Arora, N. K., Lawrence, W. & Street Jr, R. L. 2011. Measuring patient-centered communication in cancer care: A literature review and the development of a systematic approach. *Social Science & Medicine,* 72**,** 1085-1095.

Mcilfatrick, S., Sullivan, K. & Mckenna, H. 2006. Nursing the clinic vs. nursing the patient: nurses' experience of a day hospital chemotherapy service. *Journal of Clinical Nursing,* 15**,** 1170-1178.

Mckenzie, H., Hayes, L., White, K., Cox, K., Fethney, J., Boughton, M. & Dunn, J. 2011. Chemotherapy outpatients' unplanned presentations to hospital: a retrospective study. *Supportive Care in Cancer,* 19**,** 963-969.

Mead, G. H. 1956. *George Herbert Mead: On Social Psychology - Selected Papers,* (A. Strauss, Ed.) Chicago, University Of Chicago Press.

Miller, S. M. 1995. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer,* 76**,** 167-177.

Miller, S. M. 1998. Monitors and Blunters: Different Patient Coping Styles. *Oncology News International* [Online], 7.

Miller, S. M. & Mangan, C. E. 1983. Interacting effects of information and coping style in adapting to gynecologic stress: Should the doctor tell all? *Journal of personality and social psychology,* 45**,** 223.

Mills, M. E. & Sullivan, K. 1999. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *Journal of Clinical Nursing,* 8**,** 631-642.

Mishel, M. & Braden, C. 1988. Finding meaning: antecedents of uncertainty in illness. *Nursing research,* 37**,** 98.

Mishel, M. H. 1990. Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship,* 22**,** 256-262.

Mitchell, T. 2007. The social and emotional toll of chemotherapy – patients' perspectives. *European Journal of Cancer Care,* 16**,** 39-47.

Mitchell, T. & Turton, P. 2011. 'Chemobrain': concentration and memory effects in people receiving chemotherapy–a descriptive phenomenological study. *European Journal of Cancer Care,* 20**,** 539-548.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. & The, P. G. 2009. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med,* 6**,** e1000097.

Molassiotis, A., Brearley, S., Saunders, M., Craven, O., Wardley, A., Farrell, C., Swindell, R., Todd, C. & Luker, K. 2009. Effectiveness of a Home Care Nursing Program in the Symptom Management of Patients With Colorectal and Breast Cancer Receiving Oral Chemotherapy: A Randomized, Controlled Trial. *Journal of Clinical Oncology,* 27**,** 6191-6198.

Morris, S. M. & Thomas, C. 2001. The carer's place in the cancer situation: where does the carer stand in the medical setting? *European Journal of Cancer Care,* 10**,** 87-95.

Morrow, S. L. & Smith, M. L. 1995. Constructions of survival and coping by women who have survived childhood sexual abuse. *Journal of Counseling Psychology,* 42**,** 24-33.

Nathan, C. 2006. Neutrophils and immunity: challenges and opportunities. *Nat Rev Immunol,* 6**,** 173-182.

National Cancer Action Team. 2008. Connected. Participant Handbook- Advanced Communication Skills.

National Cancer Institute. 1998. Common Toxicity Criteria: Cancer Therapy Evaluation program, version 2.0. Bethesda, MD, Division of Cancer Treatment, National Cancer Institute, National Institutes of Health, Department of Health and Human Services.

National Cancer Peer Review - National Cancer Action Team 2011. Manual for Cancer Services: Chemotherapy Measures.

National Cancer Peer Review - National Cancer Action Team 2013. Manual for Cancer Services. Acute Oncology - Including Metatastic Spinal Cord Compression Measures.

National Chemotherapy Advisory Group (NCAG) 2009. Chemotherapy Services in England: Ensuring quality and safety. London.

National Confidential Enquiry into Patient Outcome and Death 2008. For better, for worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy. London: The Stationary Office.

NHS England. 2013. Chemotherapy Patient Experience Survey.

National Institute for Health and Care Excellence (NICE) 2007. Behaviour change: the principles for effective interventions.

N ational Institute for Health and Care Excellence (NICE) 2009. Promoting well being at work.

National Institute for Health and Care Excellence (NICE) 2012. Scope: Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients.

National Institute for Health Research (NIHR) Evaluation, Trials and Studies. http://www.nets.nihr.ac.uk/projects/hsdr/130749. Accessed online 01.11.14.

Nirenberg, A., Mulhearn, L., Lin, S. & Larson, E. 2004. Emergency Department Waiting Times for Patients With Cancer With Febrile Neutropenia: A Pilot Study. *Oncology Nursing Forum,* 31**,** 711-715.

Nirenberg, A., Bush, A., Davis, A., Friese, C., Gillespie, T. & Rice, R. 2006a. Neutropenia: State of the Knowledge Part I. *Oncology Nursing Forum,* 33**,** 1193-1201.

Nirenberg, A., Bush, A., Davis, A., Friese, C., Gillespie, T. & Rice, R. 2006b. Neutropenia: State of the Knowledge Part II. *Oncology Nursing Forum,* 33**,** 1202-1208.

Nirenberg, A., Reame, N., Cato, K. & Larson, E. 2010. Oncology Nurses' Use of National Comprehensive Cancer Network Clinical Practice Guidelines for Chemotherapy-Induced and Febrile Neutropenia. *Oncology Nursing Forum,* 37**,** 765-773.

Nordin, K., Liden, A., Hansson, M., Rosenquist, R. & Berglund, G. 2002. Coping style, psychological distress, risk perception, and satisfaction in subjects attending genetic counselling for hereditary cancer. *Journal of Medical Genetics,* 39**,** 689-694.

Norman, I. & Griffiths, P. 2014. The rise and rise of the systematic review. *Int J Nurs Stud,* 51**,** 1-3.

Northouse, L. L., Mood, D., Templin, T., Mellon, S. & George, T. 2000. Couples' patterns of adjustment to colon cancer. *Social Science & Medicine,* 50**,** 271-284.

Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L. & Mood, D. W. 2010. Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *CA: a cancer journal for clinicians,* 60**,** 317-339.

Northouse, L., Williams, A.-L., Given, B. & Mccorkle, R. 2012. Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology,* 30**,** 1227-1234.

Novick, G. 2008. Is there a bias against telephone interviews in qualitative research? *Research in nursing & health,* 31**,** 391-398.

Oakley, C., Johnson, J. & Ream, E. 2010. Developing an intervention for cancer patients prescribed oral chemotherapy: a generic patient diary. *European Journal of Cancer Care,* 19**,** 21-28.

Ockerby, C., Livingston, P., O'Connell, B. & Gaskin, C. J. 2012. The role of informal caregivers during cancer patients' recovery from chemotherapy. *Scandinavian Journal of Caring Sciences*, 27(1), 147-55.

Okera, M., Chan, S., Dernede, U., Larkin, J., Popat, S., Gilbert, D., Jones, L., Osuji, N., Sykes, H., Oakley, C., Pickering, L., Lofts, F. & Chowdhury, S. 2011. A prospective study of chemotherapy-induced febrile neutropenia in the South West London Cancer Network. Interpretation of study results in light of NCAG/NCEPOD findings. *British Journal of Cancer,* 104**,** 407-412.

Olsen, J., Baldwin, S. & Houts, A. 2011. The Patient Care Monitor-Neutropenia Index: Development, Reliability, and Validity of a Measure for Chemotherapy-Induced Neutropenia. *Oncology Nursing Forum,* 38**,** 360-367.

Ong, L. M., Visser, M. R., Van Zuuren, F. J., Rietbroek, R. C., Lammes, F. B. & De Haes, J. C. 1998. Cancer patients' coping styles and doctor-patient communication. *Patient Education and Counseling,* 34**,** S70-S71.

Ormandy, P. 2011. Defining information need in health–assimilating complex theories derived from information science. *Health Expectations,* 14**,** 92-104.

Parliamentary and Health Service Ombudsman 2013. Time to Act. Severe Sepsis; rapid diagnosis and treatment saves lives. London.

Partridge, A. H., Archer, L., Kornblith, A. B., Gralow, J., Grenier, D., Perez, E., Wolff, A. C., Wang, X., Kastrissios, H. & Berry, D. 2010. Adherence and persistence with oral adjuvant chemotherapy in older women with early-stage breast cancer in CALGB 49907: adherence companion study 60104. *Journal of Clinical Oncology,* 28**,** 2418-2422.

Pedersen, B., Koktved, D. P. & Nielsen, L. L. 2012. Living with side effects from cancer treatment–a challenge to target information. *Scandinavian journal of caring sciences*.

Pilgrim, D., Rogers, A. & Bentall, R. 2009. The centrality of personal relationships in the creation and amelioration of mental health problems: the current interdisciplinary case. *Health:,* 13**,** 235-254.

Pillay, J., Den Braber, I., Vrisekoop, N., Kwast, L. M., De Boer, R. J., Borghans, J. A., Tesselaar, K. & Koenderman, L. 2010. In vivo labeling with 2H2O reveals a human neutrophil lifespan of 5.4 days. *Blood,* 116**,** 625-7.

Pollock, K., Cox, K., Howard, P., Wilson, E. & Moghaddam, N. 2008. Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. *Supportive Care in Cancer,* 16**,** 963-973.

Powe, B. D., Hamilton, J. & Brooks, P. 2006. Perceptions of cancer fatalism and cancer knowledge: a comparison of older and younger African American women. *J Psychosoc Oncol,* 24**,** 1-13.

Pringle, J., Melczak, M., Aldridge, A., Snyder, M. & Smith, R. 2011. Medication adherence and its relationship to the therapeutic alliance: Results from an innovative pilot study within a community pharmacy MTM practice. *Innov. Pharm.,* 2**,** 1-16.

Protheroe, J., Rogers, A., Kennedy, A. P., Macdonald, W. & Lee, V. 2008. Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. *Implementation Science,* 3**,** 44.

Ream, E. & Richardson, A. 1996. The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. *European Journal of Cancer Care,* 5**,** 132-138.

Ream, E., Pedersen, V., Oakley, C., Richardson, A., Taylor, C. & Verity, R. 2013a. Informal carers' experiences and needs when supporting patients through chemotherapy: a mixed method study. *European Journal of Cancer Care,* 22**,** 797-806.

Ream, E., Tsianakas, V., Verity, R., Oakley, C., Murrells, T., Robert, G. & Richardson, A. 2013b. Enhancing the role of carers in the outpatient chemotherapy setting: A participatory action research project.: Florence Nightingale School of Nursing and Midwifery. Kings College London University.

Rhodes, T. & Cusick, L. 2000. Love and intimacy in relationship risk management: HIV positive people and their sexual partners. *Sociology of Health & Illness,* 22**,** 1-26.

Rhodes, T. & Cusick, L. 2002. Accounting for unprotected sex: stories of agency and acceptability. *Social Science & Medicine,* 55**,** 211-226.

Rimer, B. 1984. Informed consent: A crucial step in cancer patient education. *Health education quarterly,* 10**,** 30-42.

Robinson, M. & Robertson, S. 2013. Health information needs of men. *Health Education Journal*.

Rogers, A., Kennedy, A., Nelson, E. & Robinson, A. 2005. Uncovering the limits of patient-centeredness: implementing a self-management trial for chronic illness. *Qualitative Health Research,* 15**,** 224-239.

Roter, D. L., Hall, J. A. & Katz, N. R. 1988. Patient-physician communication: a descriptive summary of the literature. *Patient Education and Counseling,* 12**,** 99-119.

Rowland, E., & Metcalfe, A. 2014. A systematic review of men's experiences of their partner's mastectomy: coping with altered bodies. *Psycho-Oncolo*gy, 23 (9), 963–974.

Royal College of Physicians 2012. Cancer Patients in Crisis: Responding to Unmet Needs. Report of a working party. London.: RCP.

Ryan, R. M. & Deci, E. L. 2000. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American psychologist,* 55**,** 68.

Salander, P. & Henriksson, R. 2005. Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. *Lung cancer,* 50**,** 155-162.

Savage, J. 2000. Ethnography and health care. *BMJ,* 321**,** 1400–1402.

Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J. & Dibble, S. L. 2000. Family caregiving skill: development of the concept. *Research in nursing & health,* 23**,** 191-203.

Siminoff, L. A. & Step, M. M. 2005. A communication model of shared decision making: accounting for cancer treatment decisions. *Health Psychology,* 24**,** S99.

Sitzia, J. & Wood, N. 1998. Patient satisfaction with cancer chemotherapy nursing: a review of the literature. *International Journal of Nursing Studies,* 35**,** 1-12.

Skalla, K. A., Bakitas, M., Furstenberg, C. T., Ahles, T. & Henderson, J. V. Year. Patients' need for information about cancer therapy. *In:* Oncology Nursing Forum, 2004. Onc Nurs Society, 313-319.

Skinner, C. S., Champion, V., Menon, U. & Seshadri, R. 2002. Racial and Educational Differences in Mammography-Related Perceptions Among 1,336 Nonadherent Women. *Journal of psychosocial oncology,* 20**,** 1-18.

Smith, T. J., Khatcheressian, J., Lyman, G. H., Ozer, H., Armitage, J. O., Balducci, L., Bennett, C. L., Cantor, S. B., Crawford, J., Cross, S. J., Demetri, G., Desch, C. E., Pizzo, P. A., Schiffer, C. A., Schwartzberg, L., Somerfield, M. R., Somlo, G., Wade, J. C., Wade, J. L., Winn, R. J., Wozniak, A. J. & Wolff, A. C. 2006. 2006 Update of Recommendations for the Use of White Blood Cell Growth Factors: An Evidence-Based Clinical Practice Guideline. *Journal of Clinical Oncology,* 24**,** 3187-3205.

Stewart, M. A. 1995. Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian Medical Association Journal,* 152**,** 1423.

Stiegelis, H. E., Hagedoorn, M., Sanderman, R., Bennenbroek, F. T., Buunk, B. P., Bergh, A., Botke, G. & Ranchor, A. V. 2004. The impact of an informational self-management intervention on the association between control and illness uncertainty before and psychological distress after radiotherapy. *Psycho-Oncology,* 13**,** 248-259.

Strauss, A. 1987. *Qualitative analysis for social scientists.* Cambridge, England, Cambridge University Press.

Strauss, A. & Corbin, J. M. 1997. *Grounded theory in practice,* London, Sage Publications.

Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B. & Wiener, C. 1984. *Chronic illness and the quality of life*, Mosby St. Louis.

Street, R. L. 1991. Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Social Science & Medicine,* 32**,** 541-548.

Sullivan, T., Harrold, K., Bell, K., Griffin, C., & Scarlett, C. 2013. Benefits of attending nurse-led pre-chemotherapy group sessions. *Cancer Nursing Practice,* 12(1), 27-31.

Talley, J. 2011. Metaphor, Narrative, and the Promotion of Public Health. *Genre,* 44**,** 405-423.

Tarozzi, M. 2012. International Summer School on Qualitative Research Methods in Education III Edition. *Advanced Grounded Theory.* University of Trento - Rovereto, Italy, Department of Cognitive Sciences and Education.

The UK Sepsis Trust 2012. The UK Sepsis Trust: Sepsis a guide for patients and relatives. Accessed 20.11.14.

The UK Sepsis Trust. 2013. *http://sepsistrust.org/wp-content/uploads/2013/10/briefing.pdf In background. Accessed 28.1.14.* [Online].

Thorne, S. E. 1999. Communication in cancer care: What science cannot teach us. *Cancer Nursing,* 22**,** 370-379.

Timmermans, S. & Tavory, I. 2010. Advancing ethnographic research through grounded theory practice. *In The Sage Handbook of Grounded Theory.* A. Bryant and K. Charmaz (Eds) London: Sage Publications.

Treacy, J. T. & Mayer, D. K. Year. Perspectives on cancer patient education. *In:* Seminars in oncology nursing, 2000. Elsevier, 47-56.

Tsang, J., Rudychev, I. & Pescatore, S. 2006. Prescription compliance and persistency in chronic myelogenous leukemia (CML) and gastrointestinal stromal tumor (GIST) patients (pts) on imatinib (IM). *J Clin Oncol,* 24**,** 6119.

Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G. & Hollins, S. 2009. People with learning disabilities who have cancer: an ethnographic study. *The British Journal of General Practice,* 59**,** 503.

US Department of Health and Human Sciences 2009. Common Terminology Criteria for Adverse Events (CTCAE). *Version 4.* National Institute of Health, National Cancer Institute.

Van Der Molen, B. 2000. Relating information needs to the cancer experience. 2. Themes from six cancer narratives*. *European Journal of Cancer Care,* 9**,** 48-54.

Vansteenkiste, M., Williams, G. C. & Resnicow, K. 2012. Toward systematic integration between self-determination theory and motivational interviewing as examples of top-down and bottom-up intervention development: autonomy or volition as a fundamental theoretical principle. *Int J Behav Nutr Phys Act,* 9**,** 23.

Vincent, J. L., Sakr, Y., Sprung, C. L., Ranieri, V. M., Reinhart, K., Gerlach, H., Moreno, R., Carlet, J., Le Gall, J. R. & Payen, D. 2006. Sepsis in European Intensive Care Units; results of the SOAP study. *Critical Care Medicine,* 34, 344-353.

Venetis, M. K., Robinson, J. D., Turkiewicz, K. L. & Allen, M. 2009. An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Education and Counseling,* 77**,** 379-383.

Wagner, L., Beaumont, J., Ding, B., Malin, J., Peterman, A., Calhoun, E. & Cella, D. 2008. Measuring health-related quality of life and neutropenia-specific concerns among older adults undergoing chemotherapy: validation of the Functional Assessment of Cancer Therapy–Neutropenia (FACT-N). *Supportive Care in Cancer,* 16**,** 47-56.

Waitzkin, H. 1985. Information giving in medical care. *Journal of health and social Behavior***,** 81-101.

Walker, J., Hansen, C. H., Martin, P., Symeonides, S., Ramessur, R., Murray, G. & Sharpe, M. 2014. Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data. *The Lancet Psychiatry*.

Weingart, S. N., Spencer, J., Buia, S., Duncombe, D., Singh, P., Gadkari, M. & Connor, M. 2011. Medication safety of five oral chemotherapies: a proactive risk assessment. *Journal of Oncology Practice,* 7**,** 2-6.

Wiles, R. & Kinmonth, A.-L. 2001. Patients' understandings of heart attack: implications for prevention of recurrence. *Patient Education and Counseling,* 44**,** 161-169.

Wilkinson, S., Perry, R., Blanchard, K. & Linsell, L. 2008. Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomized controlled trial: *Palliative medicine,* 22(4), 365-75.

Wright, E. B., Holcombe, C. & Salmon, P. 2004. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ,* 328**,** 864.

Youngson, R. 2011. Compassion in healthcare - the missing dimension of healthcare reform. *In:* Renzenbrink, I. (ed.) *Caregiver stress and staff support in illness, dying, and bereavement.* Oxford University Press.

Zakowski, S., Valdimarsdottir, H., Bovbjerg, D., Borgen, P., Holland, J., Kash, K., Miller, D., Mitnick, J., Osborne, M. & Van Zee, K. 1997. Predictors of intrusive thoughts and avoidance in women with family histories of breast cancer. *Annals of Behavioral Medicine,* 19**,** 362-369.

Appendices

Appendix 1: Scoping review: Characteristics of included papers

Reference	Country	Study population and sampling	Methodology	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Neutropenic sepsis clinical guidelines					
US Department of Health and Human Sciences, (2009) (CTCAE)	USA	Cancer patients undergoing chemotherapy	Literature review	CTCAE: Widely used grading system for neutropenia (see table 2.4). $^{(1)}$ Suspect sepsis if temperature 38.3^{0}C, or 38^{0}C for > 1 hour. $^{(1).}$	**High:** Validated measure
Dellinger et al., (2012)	Ten countries / four continents	General population with sepsis.	Literature review	IV broad spectrum antimicrobials should be administered within one hour of sepsis recognition. $^{(1)}$	**High:** GRADE (validated tool) applied to assess quality of studies.
NICE, (2012)	UK	Patients with cancer and sepsis.	Systematic literature review.	IVABS within 1 hour $^{(1)}$ (low quality evidence). Suspect NS if temperature >38^{o}C, or clinical signs of sepsis $^{(1)}$ (high evidence). Poor prognosis: Mucositis, temp >39^{o}C, infection, chills, confusion $^{(1)}$ (low evidence). Early symptoms $^{(2)}$ and patient education $^{(4)}$ (low evidence).	**High:** Comprehensive systematic review
The UK Sepsis Trust, (2012)	UK	General sepsis population.	Literature review.	Symptoms of severe sepsis $^{(1)}$ (see table 2.7).	**High**
The UK Sepsis Trust, (2013)	UK	General sepsis population.	Literature review.	Administer intravenous antibiotics and fluids within one hour. $^{(1)}$.	**High**
Aapro et al., (2006; 2011) (EORTC)	European / Nine countries	Cancer patients undergoing chemotherapy.	Systematic literature review.	High risk indices for NS: Chemotherapy > 20% risk of causing neutropenia, age ≥65 years, advanced disease, no antibiotic cover. $^{(1)}$	**High:** Weighted evidence with a grading system developed by ASCO.
Klastersky et al., (2000) (MASCC)	Six countries / four continents	Consecutive patient episodes of NS (n=757)	Quantitative. Validation of MASCC	High risk indices for complications from NS: Age >60 years, haematological malignancy and co-morbidities. $^{(1)}$	**High:** Validated. Detects patients with low risk NS.
Smith et al., (2006) (ASCO)	USA	Cancer patients undergoing chemotherapy	Literature review.	High risk indices for NS: Regimens with high (>20%) risk of causing neutropenia; age>65 years, advanced disease, co-morbidities. $^{(1)}$	**High:** Comprehensive literature review.

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** ASCO (American Society of Clinical Oncology); CTCAE (Common Terminology Criteria for Adverse Events); EORTC (European Organisation for Research and Treatment of Cancer); GRADE (Grading of Recommendations, Assessment Development and Evaluation); IVABs (Intravenous Antibiotics); MASCC (Multinational Association for Supportive Care in Cancer); NS (Neutropenic Sepsis); NICE (National Institute of Clinical Excellence.

(Appendix 1: continued)

Reference	Country	Study population and sampling	Methodology	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Cancer guidelines					
NCEPOD, (2008)	UK	546 cancer deaths (83 related to neutropenic sepsis).	Quantitative, and qualitative	Identified poor clinical practice in relation to neutropenia. (1) Patients delayed presentation with NS symptoms by ≥ 24- hours which may contribute to increased mortality risk. (1)	**Moderate:** Expert review. **Low:** Relied on clinician reports to identify time of delayed presentation.
NCAG, (2009)	UK	Cancer patients undergoing chemotherapy	Expert panel.	Recommend patient education is improved. (4) Recommend 24-hour on-call services are provided for cancer patients during chemotherapy. (4)	**Low:** (opinion). **Low:** (opinion).
Royal College of Physicians, (2012)	UK	Acute oncology admissions (n=262) Sampling method unclear.	Patient experience Survey	68% of admissions associated with feeling unwell or fever. (1) Some patients delayed presenting with NS for ≥ 2 days. (3)	**Moderate:** Relied on patient reports
National Cancer Peer Review, (2011)	UK	Chemotherapy measures	Expert opinion.	Expect 24-hour on-call services to be in place for cancer patients during Chemotherapy. (4)	**Low:** (opinion).
National Cancer Peer Review, (2013)	UK	Acute oncology measures	Expert opinion.	Require emergency cancer services to be in place. (4)	**Low:** (opinion).

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** NCAG (National Chemotherapy Advisory Group); NCEPOD (National Confidential Enquiry into Patient Outcomes and Death).

(Appendix 1: continued)

Reference	Country	Study Population and Sampling	Aims of the Study	Methodology	Outcome Measure(s)	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence Rating for quality of findings
Primary Research: Effects of neutropenia on symptoms and functioning							
Fortner et al., (2005a)	USA	71 patients with Lung, breast or ovarian cancer or Lymphoma. Convenience sampling	To determine differences in symptoms and functioning between grades of neutropenia	Quantitative. Longitudinal. Questionnaire. Single site. ANC data.	**Symptoms and functioning. Validated Measures:** CTCAE, SF-36; HADs. **Study Specific Measure :** CCM.	Reduced physical and social functioning in grade 4 compared to grades 0-3 neutropenia. (2)	**Low:** Convenience sampling and small sample.
Fortner et al., (2006)	USA	84 patients mainly with breast or lung cancer. Convenience sampling.	To determine differences in symptom and functioning between grades of neutropenia	Quantitative. Longitudinal. Questionnaire. ANC data.	**Symptoms and functioning. Validated Measures:** RSC, HAD, SF-36. **Study Specific Measure:** CCM-MIS.	Reduced physical and social functioning in grades 3-4 compared to grades 0-2 neutropenia. (2)	**Low:** Convenience sampling and small sample.
Fortner et al., (2005b)	USA	34 patients (100 interviews) Convenience sampling. Mainly breast or lung cancer.	To determine symptom and functioning changes with grade 4 neutropenia	Qualitative. Longitudinal. Interview. ANC data.	**Symptoms and functioning** Qualitative analysis. Method not stated.	Neutropenia associated with reduced physical and social functioning. (2)	**Low:** Convenience sampling. No comparison between grades.
Fortner and Houts, (2006)	USA	51 patients, Convenience sample**.** Mostly, lung, breast or haematological cancers.	Validation of the PCM-N Patient Care Monito.r	Quantitative. Patient Questionnaire. ANC data.	**Study Specific Measures** CCM , CCM-MIS and CCM Neutropenia index.	Reduced physical and social function in grades 3-4 compared to grades 0-2 neutropenia. (2)	**Low:** Only 51 (741) patients were eligible.

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** ANC (Absolute Neutrophil Count); CCM (Cancer Care Monitor); CCM-MIS (Cancer Care Monitor-Medical Isolation Scale); HAD (Hospital Anxiety and Depression Scale) RSCL (Rotterdam Symptom Checklist); SF-36 (Medical Outcomes Study Health Survey).

(Appendix 1: continued)

Reference	Country	Study Population and Sampling	Aims of the Study	Methodology	Outcome Measure(s)	Important findings Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence Rating for quality of findings
Primary Research: Effects of neutropenia on symptoms and functioning continued							
Nirenberg et al., (2004)	USA	19 patients (23 visits) with solid organ cancer, myeloma and NHL. Convenience sample.	To determine time to treatment for NS in emergency departments.	Quantitative. Prospective. Descriptive.	Risk factors. Presenting symptoms. Mean time to treatment. No tools described to assess research outcomes.	Mucositis: 7 (37%) of cases. (2) Mean delay in presenting: 21 hours (range 1-72). (3) Patients with co-morbidities or advanced cancer presented later. (3)	**Low:** Small convenience sample, failed to capture all NS episodes. Relied on patient reports.
Wagner et al., (2008)	USA	Patients on chemotherapy for lymphoma, lung, breast, or ovarian cancer. (n=852). Convenience sample	To establish the psychometric properties of the FACT-N	Quantitative. Prospective. Validation of FACT-N subscale.	Symptoms and functioning. **Validated Measure:** HADS. **Study Specific Measure:** FACT-N.	Detected negative effects of neutropenia on symptoms and functioning. (2)	**Low**: Convenience sample. The FACT-N could not distinguish between grades of neutropenia.
Olsen et al., (2011)	USA	424 (4 groups). Included samples from Fortner and Houts (2006) and Fortner et al (2005b).	Evaluation of Psychometric Properties of the PCM-N.	Quantitative. Self-report instrument. PCM-N score. ANC. Febrile status.	Symptoms and functioning. No tools described to assess research outcomes.	Strong internal consistency (0.81-0.91). Scores of 20 out of 130 are sensitive to 81% of patients with grades 3-4 neutropenia and 78% without neutropenia. (2)	**Moderate:** Strong internal consistency suggests the PCM-N is an internally valid model.

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** FACT-N (The Functional Assessment of Cancer Therapy-Neutropenia Instrument); NHL (Non Hodgkins Lymphoma); PCM-N Patient Care Monitor Index 1.0 Revised –Neutropenia Index).

(Appendix 1: continued)

Reference	Country	Study Population and Sampling	Aims of the Study	Methodology	Outcome Measure(s)	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence rating for quality of findings
Primary Research: Effects of neutropenia on symptoms and functioning continued							
McKenzie et al (2011)	Australia	363 cancer admissions Fever and or FN 85 (23.4%). Mostly breast, lung or colorectal cancer diagnosis. Convenience sampling.	To understand reasons and number of unplanned oncology admissions.	Quantitative. Retrospective.	Unplanned admission Incidence. Reasons for unplanned admissions. Time since chemotherapy.	Symptoms (not just FN) frequently present for 2-7 days prior to hospital presentation. (3) No data provided to suggest the number of patients with FN.	**Low:** Convenience sampling, no tools described to assess research outcomes.
Higgins and Hill (2012)	UK	53 patient survey responses. 88 patient case note reviews. Convenience sampling.	To audit a NS clinical pathway.	Retrospective audit of NS admissions.	Presenting symptoms. Morbidity. Mortality. Time to antibiotics.	Presenting symptoms: Fever < 36^{o}C (n=2), 37.5^{o}C-40^{O}C (n=68), $\geq$ 36^{O}C - $\leq$37.2^{o}C (n=88). (2) Thirty (34%) patients waited > 24 hours before presenting. (3) Data missing for 10 patients.	**Low:** Relied on self-report and did not capture all episodes. Study design did not incorporate finding out what information and support assist patients to access help for NS.

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis.

(Appendix 1: continued)

Reference	Country	Study Population and Sampling	Aims of the Study	Methodology	Outcome Measure(s)	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence Rating for quality of findings
Primary research: Mortality and morbidity associated with neutropenic sepsis							
Okera et al., (2011)	UK	64 cancer patients (71 admissions with NS). Mainly with breast cancer or a haemto oncology diagnosis. Sampling: attempted to capture all episodes.	Compare findings from NCAG and NCEPOD with organisational, clinical and patient aspects of NS.	Prospective Audit	Morbidity. Mortality. Symptoms. Management of febrile neutropenia. **Study Specific Measure** Non validated 58-item proforma	Demographics: Advanced disease 39 (54%). Age >65years 25(35%). Previous NS 18(25%). No G-CSF or antibiotic 43(60%). Chemotherapy > 20% risk 23(32%). (1) Mortality 3(4.2%). (1) Infections: respiratory 35(49%), GI 33 (46%), mucositis 13 (18%). (2)	**Low:** Small sample. Could not identify all episodes of NS.
Kuderer et al., (2006)	USA	41,779 cancer hospital admissions for neutropenic sepsis. Convenience sampling	To identify NS morbidity, mortality and costs to the health services.	Audit	Mortality. Length of stay Cost per admission. No tools described to assess research outcomes.	Mortality rate 9.5% (range 0-50%). (1) Risk factors for mortality included co-morbidities. (1) Cost estimate $1.06 billion.	**Low:** Data may be incomplete due to coding issues.
Chirvella et al., (2009)	Spain	793 patients undergoing adjuvant chemotherapy for breast cancer. Convenience sampling.	To evaluate dose response effect of adjuvant chemotherapy.	Quantitative	Disease free survival. Overall survival.	Disease free survival is positively affected by reduced treatment delays and maintaining dose intensity. (1)	**High:** Large study (n=793). Valid and reliable outcome measures. Clinically important findings.
Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis							

(Appendix 1: continued)

Reference	Country	Study Population	Aims of the Study	Methodology	Outcome Measure(s) Tools applied to assess research outcome(s)	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Evidence Rating for quality of findings
Primary research: Mortality and morbidity associated with neutropenic sepsis continued							
Vincent et al., (2006)	European	3,147 patients with sepsis from 198 intensive care units in 24 countries.	To define the incidence of sepsis and characteristics of critically ill patients	Quantitative. Longitudinal. Cohort. Multiple centre. Observation centre.	Site of infection. Prognostic indicators. Infective organism. No tools described to assess research outcomes	Important prognostic variables: Older age (OR,1.0 per year;95% CI, 1.0-1.0, p< .001); Co morbidities (OR, 2.8; 95% CI 1.06-5.0 P<.001). (1)	**High:** Large sample (n=3,147). Valid and reliable outcome measures. Clinically important findings
Malik et al., (2001).	Pakistan	576 NS episodes. 22 (3.8%) patients presented with septic shock.	To identify the incidence of septic shock, characteristics of presenting patients and association with morbidity and mortality.	Quantitative. Prospective.	Morbidity and mortality. No tools described to assess research outcomes,	Most patients in shock presented to A&E. They were older and had advanced disease. (1) Symptoms of septic shock included diarrhoea, altered mental state, bleeding and dyspnoea. (1) Patients delayed presenting. (3)	**Low:** underpowered to detect differences - 22 (3.8%) of 576 episodes were related to septic shock. Delayed time to presentation is unclear.
Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis.							

Appendix 1: continued

Reference	Country	Study Population	Methodology	Important findings (Superscript numbers refer to foot note, indicating relevance to scoping review themes)	Rating or strength of the evidence
Information and support					
Nirenberg et al., (2006b)	USA	n/a	Review of clinical guidelines. Literature review.	Inconsistent guidelines, including symptoms of NS. (2) Poor evidence to guide NS education for patients. (4)	**Low:** Method for review is not presented.
Nirenberg et al., (2010)	USA	4000 cancer nurses (309 participated)	Cross sectional survey design; descriptive, correlational analysis	Knowledge and confidence in identification of patients at risk of NS increased with greater experience and education. (1) 84% of nurses claimed they risk assessed and educated patients about NS. 61% of nurses were unaware that NS is most likely after the first chemotherapy. (4)	**Low:** Low response rate (50%). 309 suitable responses from 4000 nurses approached. Locally developed survey that did not appear piloted or validated.
Higgins,(2008)	UK	57 patients	Patient survey to evaluate their experience of having a chemotherapy alert card	89% of patients had an alert card. 82% kept it with them. Patients felt reassured there was a 24-hour on-call service. (4)	**Low:** Convenience sampling, the survey did not appear piloted or validated. Study design did not incorporate establishing if the alert card promoted early presentation with NS.

Scoping review themes: (1) Defining neutropenic sepsis and the risks of this to patients undergoing chemotherapy for cancer. (2) Symptoms of neutropenic sepsis that patients should report to clinicians. (3) Knowledge about delayed patient presentation to hospital with neutropenic sepsis. (4) Education of patients about neutropenic sepsis. **Abbreviations:** CIN (chemotherapy induced neutropenia).

Appendix 2: Permissions table

Table/ Figure	Page	Reference	License agreement with	License number	Date of permission
Figure 2.1	20	Moher, D., Liberati A., Tetzlaff J., Altman DG. (2009) Preferred reporting items for systematic reviews and meta-analyses; the PRISMA statement. BMJ: 339:b2535do:10.1136/bmj.b2535.	British Medical Journal	3395901345461	25.5.14
Figure 2.2	32	2010 update of EORTC guidelines for the use of granulocyte-colony stimulating factor to reduce the incidence of chemotherapy-induced febrile neutropenia in adult patients with lymphoproliferative disorders and solid tumours.	Elsevier	3285951249331	11.12.13
Figure 2.3	34	The Multinational Association for Supportive Care in Cancer Risk Index: A Multinational Scoring System for Identifying Low-Risk Febrile Neutropenic Cancer Patients.	American Society of Clinical Oncology	3285960596185	11.12.13
Figure 3.1 3.2 3.3 8.1 8.2	58 61 70 200 219	Epstein RM., Street RL Jr. (2007). Patient-centred Communication in Cancer Care; Promoting Healing and Reducing Suffering, Bethesda, MD: National Cancer Institute, USA.	Dr Ronald Epstein	Permission via e-mail	11.12.13
Figure 4.1	99	Tarozzi. M. (2012). Constructivist grounded theory coding process. Presented at Grounded Theory Summer School, University of Trento, Rovereto, Italy	Professor Massimiliano Tarozzi	Permission via e-mail	12.3.13

(Appendix 2: continued)

Table/ Figure	Page	Reference	License agreement with	License number	Date of permission
Figure 4.4 7.1	 104 190	Morrow SL., and Smith ML., (1995). A grounded theory study, constuctions of survival and coping by women who have survived childhood sexual abuse, in Qualitative Inquiry and Research Design Choosing Among Five Traditions, Creswell JW. (ed)297-321, Sage Publications, London.	Sage Publications, Inc. Books	3290930275611	16.12.13
Figure 4.5	105	Tarozzi, M. (2008). Che cos[1]è la grounded theory. Roma: Carocci.	Professor Massimiliano Tarozzi	Permission via e-mail	12.3.13
Table 2.3	25	CASP (Critical Appraisal Skills Programme) Qualitative Research Checklist (2014) Critical Appraisal Skills Programme (CASP) 2014. CASP Checklists (Oxford) *http://www.casp-uk.net/#!casp-tools-checklists/c18f8*	CASP. Oxford	Permission via e-mail	27.5.14
Table 2.4	26	Clinical Review From Quantitative Studies (Law et al 1998) www.srs-mcmaster.ca/Portals/20/pdf/ebp/quanreview_form1.doc	Professor Mary Law, McMaster University, USA	Permission by e-mail	26.5.14
Table 2.7	41	Reused with permission from “The Patient Care Monitor-Neutropenia Index: Development, Reliability, and Validity of a Measure for Chemotherapy-induced Neutropenia,” by J.P. Olsen, S. Baldwin, & A.C. Houts, 2011, *Oncology Nursing Forum, 38*(3), 360-367. Copyright 2011 by Oncology Nursing Society.	Oncology Nursing Society	Permission via e-mail	11.12.13

Appendix 3: Steering group terms of reference and minutes

KING'S College LONDON

University of London

Neutropenic Sepsis Study Steering Group

Terms of Reference

PURPOSE

- To advise on research, which is being carried out by Catherine Oakley, who is a nurse and PhD student at Kings College London, University.
- The research is looking at why chemotherapy patients sometimes delay presenting to hospital with a low white count (neutropenic sepsis). The study title is: **How are risks of neutropenic sepsis conveyed to, and interpreted by, patients undergoing chemotherapy and their carers?**

MEMBERS

- There are 12 members who include patients and carers, a doctor, researchers, senior chemotherapy/cancer nurses and a cancer information specialist.

COMMITMENT

- To attend three meetings between July 2012 and April 2015.
- The meetings will last between 60-90 minutes.
- To discuss the research findings, as these develop, to get different views on these.
- To refine the research question.
- To provide guidance on new questions to ask patients, carers and clinicians to make sure the researcher does not miss anything important and obtains as complete a picture as possible.
- Minutes of the meeting will be kept and information gathered will be referred to in the final report findings. Information that could identify any member of the steering group will not be included in the final report.
- Discussions will be kept confidential.

REFRESHMENTS AND REIMBURSEMENT

- Refreshments will be provided during the meeting.
- Travel expenses will be funded.

If you have any questions or concerns about the steering group, please contact the researcher, Catherine Oakley on 07989659857

Agreed 23.07.12

KING'S College LONDON
University of London

Neutropenic Sepsis Study Steering Group.

Minutes of Meeting One Held on 23rd July 2012

Present:

CO	NIHR Research Fellow
Dr JM	Consultant Medical Oncologist
KS	Patient Representative
AM	Carer Representative
PB	Patient Representative
AW	Cancer Information Specialist, Dimbleby Cancer Care
AH	Acute Oncology Nurse.
DH	Patient Representative

Apologies

LL	Patient Representative
EG	Carer Representative
MF	Chemotherapy Nurse Consultant

1. Welcome and Introductions

CO introduced the meeting and explained the purpose as detailed in the terms of reference. Essentially, her PhD research is looking at why patients sometimes delay presenting to hospital with symptoms of neutropenic sepsis. This is a complication of chemotherapy which is life threatening and requires urgent hospital treatment with intravenous antibiotics.

The group agreed they were able to provide advice on areas of research enquiry and questioning. Three meetings will be held. The second meeting will focus on the emerging results. The final results will be presented at the last meeting when ideas will be generated for an intervention to be tested in a subsequent study.

The group introduced themselves and shared their experience of chemotherapy and any experience of neutropenic sepsis. AH spoke about her experience of developing a patient chemotherapy alert card which has been used nationally. She also told us about a recent neutropenic sepsis admission audit, which found 50% of patients delayed presenting to hospital by at least 24 hours.

AW said that patients have told her they do not like to bother the helpline, that information is sometimes confusing and they sometimes get mixed messages. Patients often say they are not sure of the process for calling.

PB told us his wife was diagnosed with Bowel cancer in 2009 and is currently in remission having undertaking 6 months (12 cycles) of Chemotherapy. PB is currently working as a manager of an Advocacy service supporting a variety of clients in the mental health, mental capacity and learning disabilities arena. He deals with diverse issues, including accommodation, safeguarding, care reviews and serious medical treatment issues.

JM thought it would be helpful for the group to understand that neutrophils are a type of white blood cell, needed to fight infection. It is a reduction in neutrophils that can lead to neutropenic sepsis. JM has also recently been a member of the acutely ill cancer patient working group at the Royal College of Physicians. The group has carried out a national patient survey and will be launching guidance for patients and healthcare professionals to improve emergency cancer care. The group have developed a patient wallet to help patients navigate the healthcare system.

KS, DH and AM are all members of a CPWG (Chemotherapy Patient Working Group). We heard that patients are often frightened before they start chemotherapy, when they are trying to take information in. Early signs of neutropenic sepsis may be subtle and more obvious to others (friends, family, and colleagues) than the patient. Patients may not feel that unwell to start with and the deterioration can be surprisingly fast. As AW mentioned, patients sometimes don't want to bother the staff. When patients come into hospital issues include accessing veins. This is a particular problem for breast patients who often have limited venous access due to a risk of lymphoedema.

2. Outline of research and discussion

CO presented her research methodology which involves observing breast cancer patients being given information about chemotherapy side effects by doctors in outpatient clinics and by chemotherapy nurses in a chemotherapy day unit. She is also interviewing patients who have been admitted to hospital with neutropenic sepsis as well as doctors, patients and carers. Our discussion continued and the group came up with additional aspects for CO to look out for during interviews and observation

Things to look out for:

- Be aware that the Patient-centred Communication model is American and they have a different model of health care. They may prepare patients for chemotherapy differently to the UK.
- How do people feel about presenting themselves with the alert card to A&E?
- Does age/culture impact on behaviour in terms of reporting symptoms of neutropenic sepsis?
- How do patients perceive information from other patients compared to healthcare professionals?
- What happens if patients do not have a carer?
- How clear are messages about picking up symptoms and calling?
- What impact might they way information is given have on reporting (Is it a tick in the box?).
- Find more out about the hotline calls. How difficult is it to get through. What are these calls about, how appropriate are these? Interview on-call doctors.
- Talk to people who had a bad experience of calling.

- Ask patients and carers how many people they have spoken to about chemotherapy and the advice given. See if there is anything different in terms of information and support between those who do and don't present early.
- Ask how people deal with other risky situations, what would their normal response be and does this differ to neutropenic sepsis?
- Flip it over – ask patients – if somebody you cared about had these symptoms what would you do?
- The group felt that patients generally do as they're told in relation to chemotherapy side effects. Why is it different with neutropenic sepsis? Is it because it's not so obvious?
- Do patients know what it feels like to have a temperature? Do they own a thermometer? Do they know how to take the temperature?
- Look at the literature around screening – do certain types of people present more readily?
- We discussed patients wanting to have a normal life e.g. going to work, going on holiday and the impact of chemotherapy treatment and infection prevention on that. We spoke about the extent we work with patients on an individual basis to identify priorities and try to accommodate these.
- Why do people think they are being a nuisance – explore further

3. AOB – None
4. Date of Next Meeting to be held mid 2013

Neutropenic Sepsis Study Steering Group.

Minutes of Meeting Two Held on 29th August 2013

Present:	
CO	NIHR Research Fellow
JM	Consultant Medical Oncologist
KS	Patient Representative
AM	Carer Representative
PB	Patient Representative
AW	Cancer Information Specialist
MF	Chemotherapy Nurse Consultant
Apologies	
AH	Acute Oncology Nurse
EG	Carer Representative
DH	Patient Representative

The aim was of the meeting was to discuss emerging study findings to share experiences and see if the findings resonate with others. Attendees agreed not to change practice based on emerging findings. The following areas were broadly discussed

1. **Telling patients about it –** need to look at other areas of research about conveying scary information
2. **Difficult Recognising it – Temperature or not**
3. **Feeling protected – think can avoid- what advice to give people –** Patients talk to AW about mixed messages
4. **Avoid or seek out information**
   Information overload. Too much going on in pre treatment consultation
   Think patients tune into a scenario/patient stories
5. **Accessing Help – reluctant to go back if had bad experience. Relationships important. What is a bad experience? Who do chemotherapy patients have a relationship with**? Not sure people know what to say to A&E. Government are saying don't go to A&E. AW – patients tell her no one is expecting them in A&E. When do patients get told to go to the GP? Mixed messages. ?NHS Helpline confusing for chemotherapy patients.
6. **Carers not engaging-** Want to help and need a job e.g. looking out for neutropenic sepsis. Discussed giving carers permission to call during the pre-treatment consultation.
7. **Ignore symptoms –** even with acute oncology service patients call and play down the temperature. Good message would be that going early to A&E is better for the patient.

Agreed to meet following completion of the research, to discuss the final findings and a new intervention study.

Appendix 4: Ethical and research and development permission

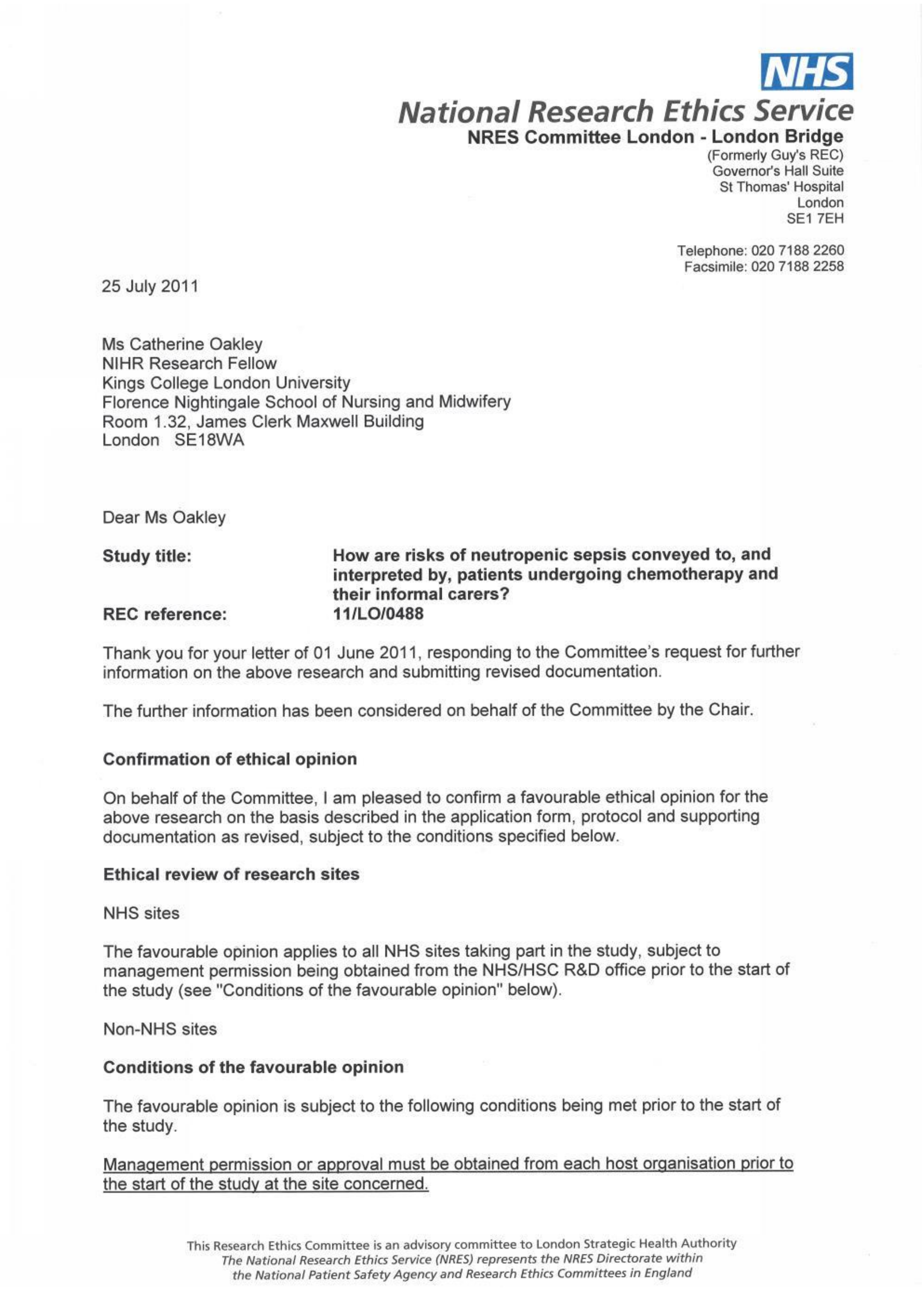
Ethical and local research and development approval were obtained as detailed below:

1. Ethical approval for the study was submitted on the 1st April 2011. Following review by the ethics committee clarification was required about action the researcher would take if she witnessed an issue of clinical concern, how contact would be made with patients and the level of participant observation. Minor changes were further required to written participant information. The proposal was amended and resubmitted and ethical approval was finally granted on the 25th July 2011.

2. Approval from the local cancer research governance committee was granted on the 4th July 2012.

3. Local research and development approval was gained on the 2nd September 2011.

4. Amendments were submitted to the ethics and the research and development offices on the 13th February 2012 and approved on the 16th March 2012. These included audio recording of consultations and informal interviews, not informing observation patients the study interest was neutropenic sepsis and inclusion of patients who received chemotherapy at the research site but who were admitted to other hospitals when they developed neutropenic sepsis.



NHS
National Research Ethics Service
NRES Committee London - London Bridge
(Formerly Guy's REC)
Governor's Hall Suite
St Thomas' Hospital
London
SE1 7EH

Telephone: 020 7188 2260
Facsimile: 020 7188 2258

25 July 2011

Ms Catherine Oakley
NIHR Research Fellow
Kings College London University
Florence Nightingale School of Nursing and Midwifery
Room 1.32, James Clerk Maxwell Building
London SE18WA

Dear Ms Oakley

Study title:	**How are risks of neutropenic sepsis conveyed to, and interpreted by, patients undergoing chemotherapy and their informal carers?**
REC reference:	**11/LO/0488**

Thank you for your letter of 01 June 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

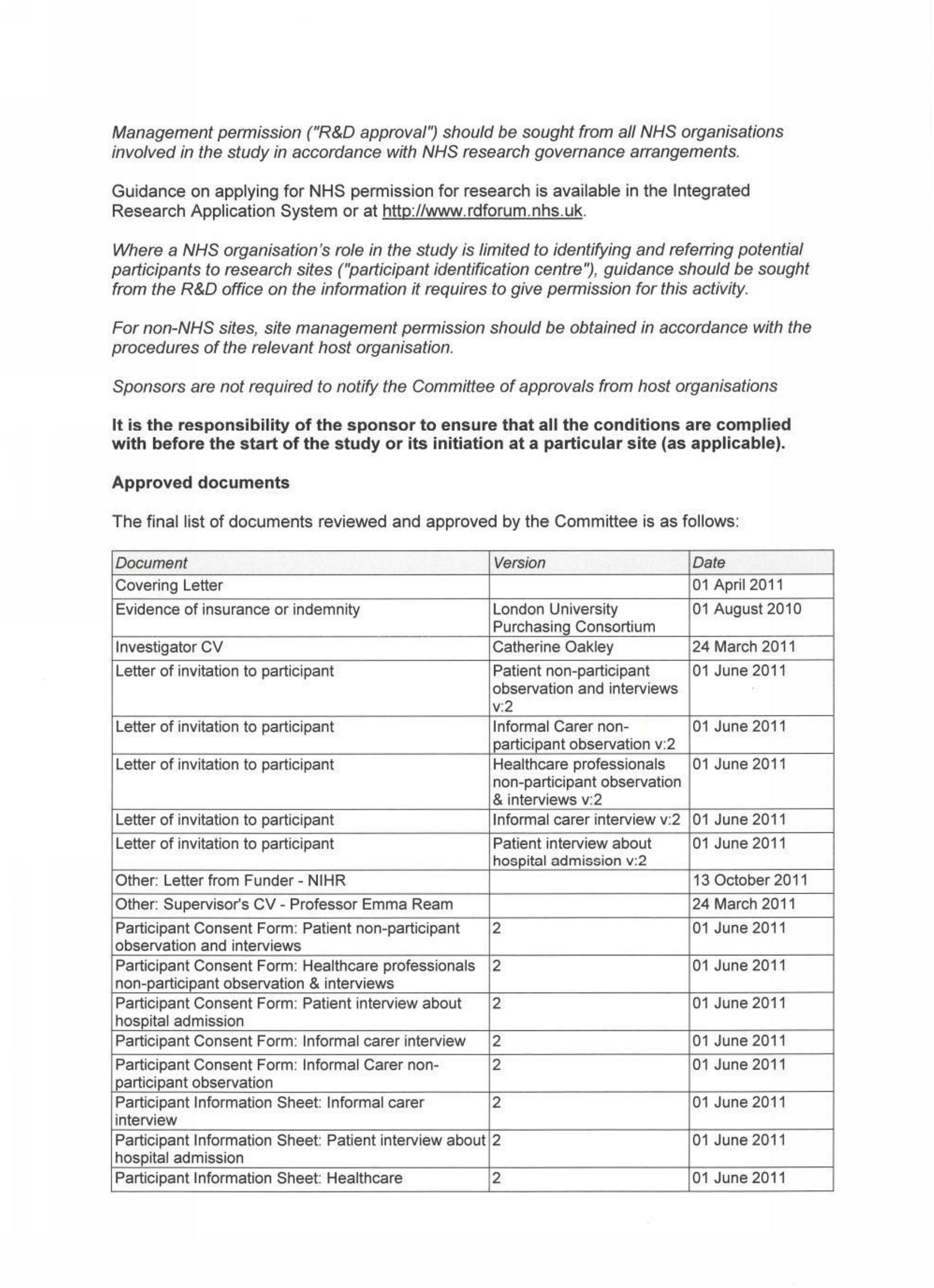
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.



Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

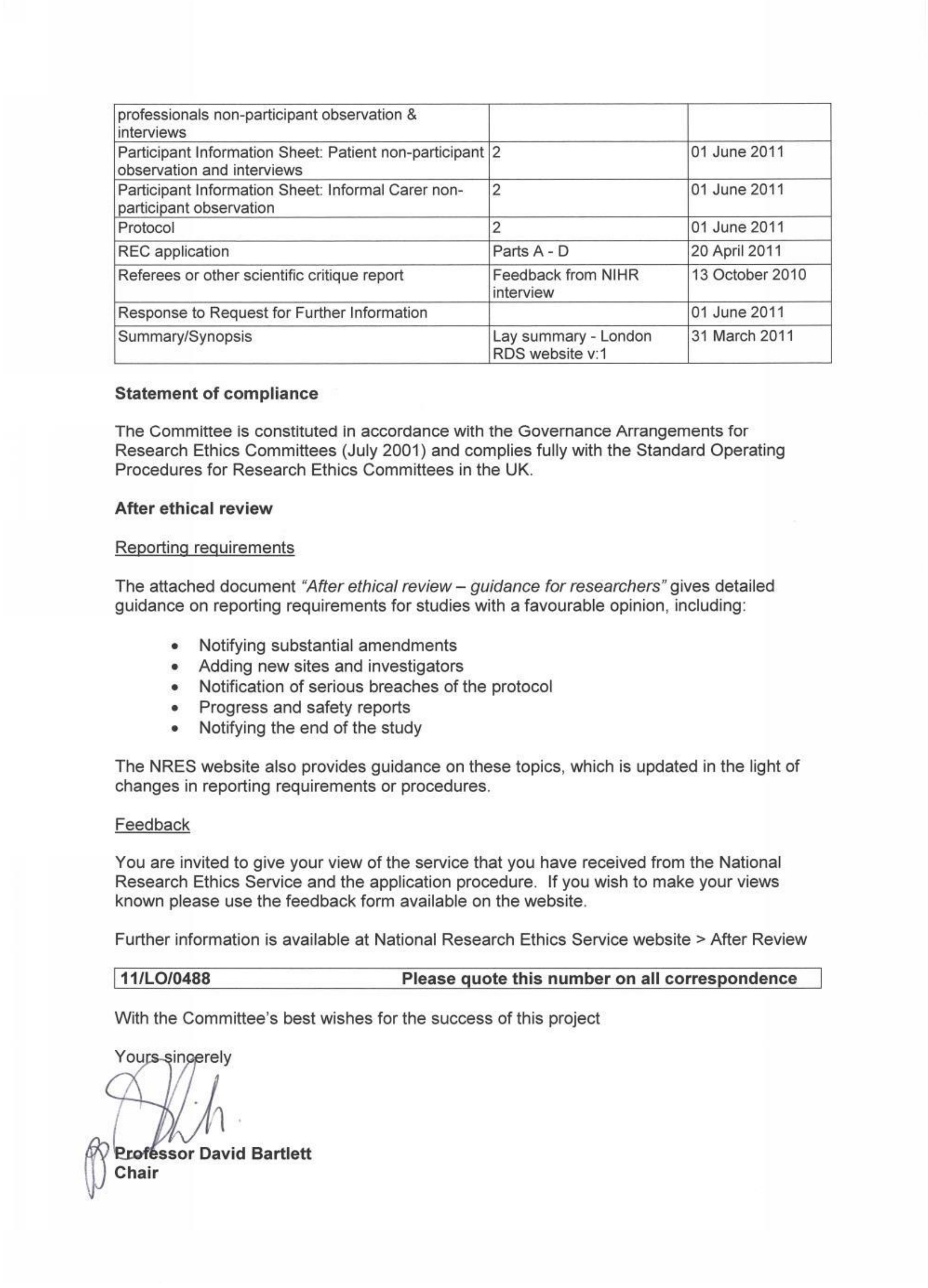
Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		01 April 2011
Evidence of insurance or indemnity	London University Purchasing Consortium	01 August 2010
Investigator CV	Catherine Oakley	24 March 2011
Letter of invitation to participant	Patient non-participant observation and interviews v:2	01 June 2011
Letter of invitation to participant	Informal Carer non-participant observation v:2	01 June 2011
Letter of invitation to participant	Healthcare professionals non-participant observation & interviews v:2	01 June 2011
Letter of invitation to participant	Informal carer interview v:2	01 June 2011
Letter of invitation to participant	Patient interview about hospital admission v:2	01 June 2011
Other: Letter from Funder - NIHR		13 October 2011
Other: Supervisor's CV - Professor Emma Ream		24 March 2011
Participant Consent Form: Patient non-participant observation and interviews	2	01 June 2011
Participant Consent Form: Healthcare professionals non-participant observation & interviews	2	01 June 2011
Participant Consent Form: Patient interview about hospital admission	2	01 June 2011
Participant Consent Form: Informal carer interview	2	01 June 2011
Participant Consent Form: Informal Carer non-participant observation	2	01 June 2011
Participant Information Sheet: Informal carer interview	2	01 June 2011
Participant Information Sheet: Patient interview about hospital admission	2	01 June 2011
Participant Information Sheet: Healthcare	2	01 June 2011



professionals non-participant observation & interviews		
Participant Information Sheet: Patient non-participant observation and interviews	2	01 June 2011
Participant Information Sheet: Informal Carer non-participant observation	2	01 June 2011
Protocol	2	01 June 2011
REC application	Parts A - D	20 April 2011
Referees or other scientific critique report	Feedback from NIHR interview	13 October 2010
Response to Request for Further Information		01 June 2011
Summary/Synopsis	Lay summary - London RDS website v:1	31 March 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/LO/0488 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

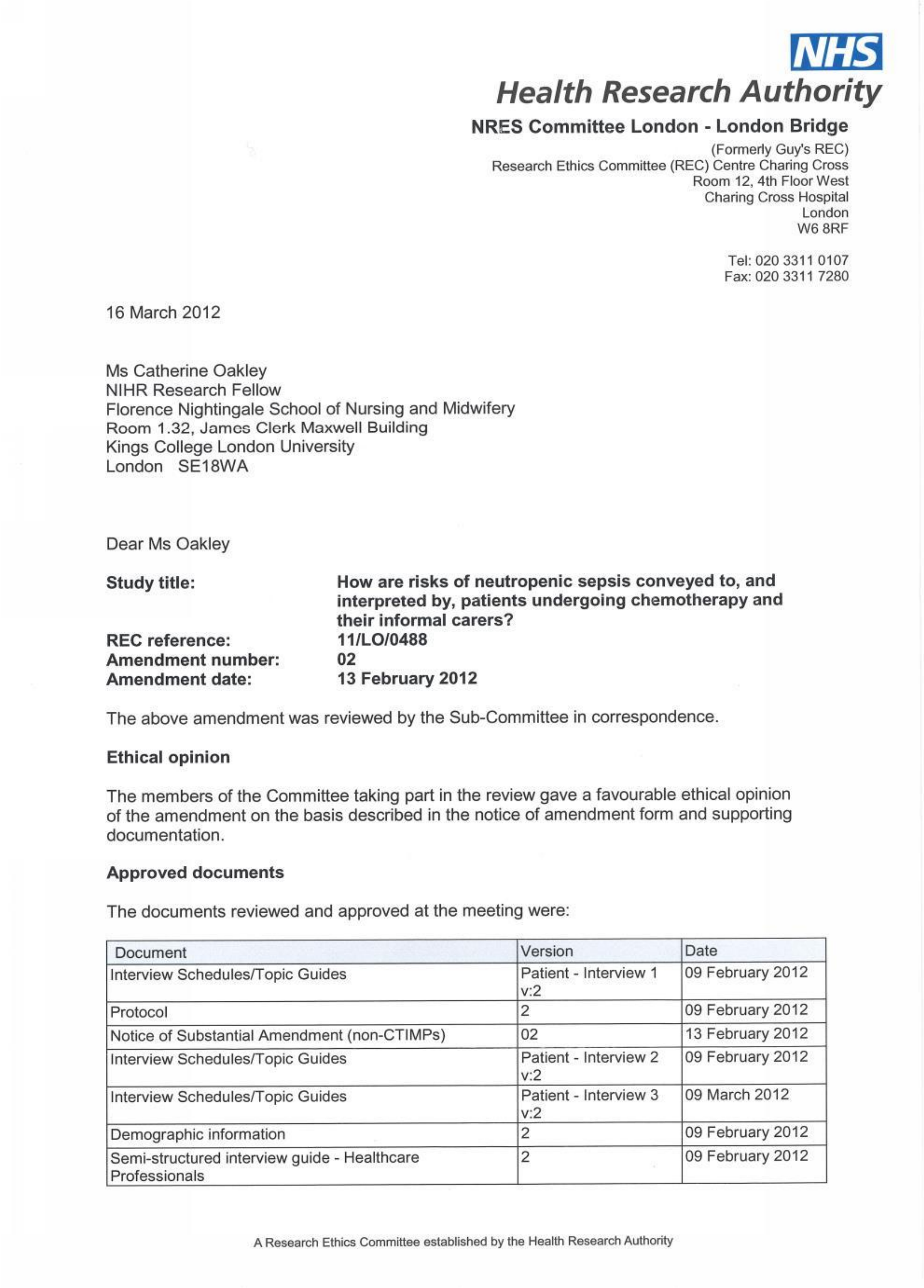
Yours sincerely

Professor David Bartlett
Chair

Email: stephanie.hill@gstt.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *SL-AR2*

Copy to: *Keith Brennan, King's College London*
R&D Department, GSTFT



NHS
Health Research Authority
NRES Committee London - London Bridge
(Formerly Guy's REC)
Research Ethics Committee (REC) Centre Charing Cross
Room 12, 4th Floor West
Charing Cross Hospital
London
W6 8RF

Tel: 020 3311 0107
Fax: 020 3311 7280

16 March 2012

Ms Catherine Oakley
NIHR Research Fellow
Florence Nightingale School of Nursing and Midwifery
Room 1.32, James Clerk Maxwell Building
Kings College London University
London SE18WA

Dear Ms Oakley

Study title:	**How are risks of neutropenic sepsis conveyed to, and interpreted by, patients undergoing chemotherapy and their informal carers?**
REC reference:	**11/LO/0488**
Amendment number:	**02**
Amendment date:	**13 February 2012**

The above amendment was reviewed by the Sub-Committee in correspondence.

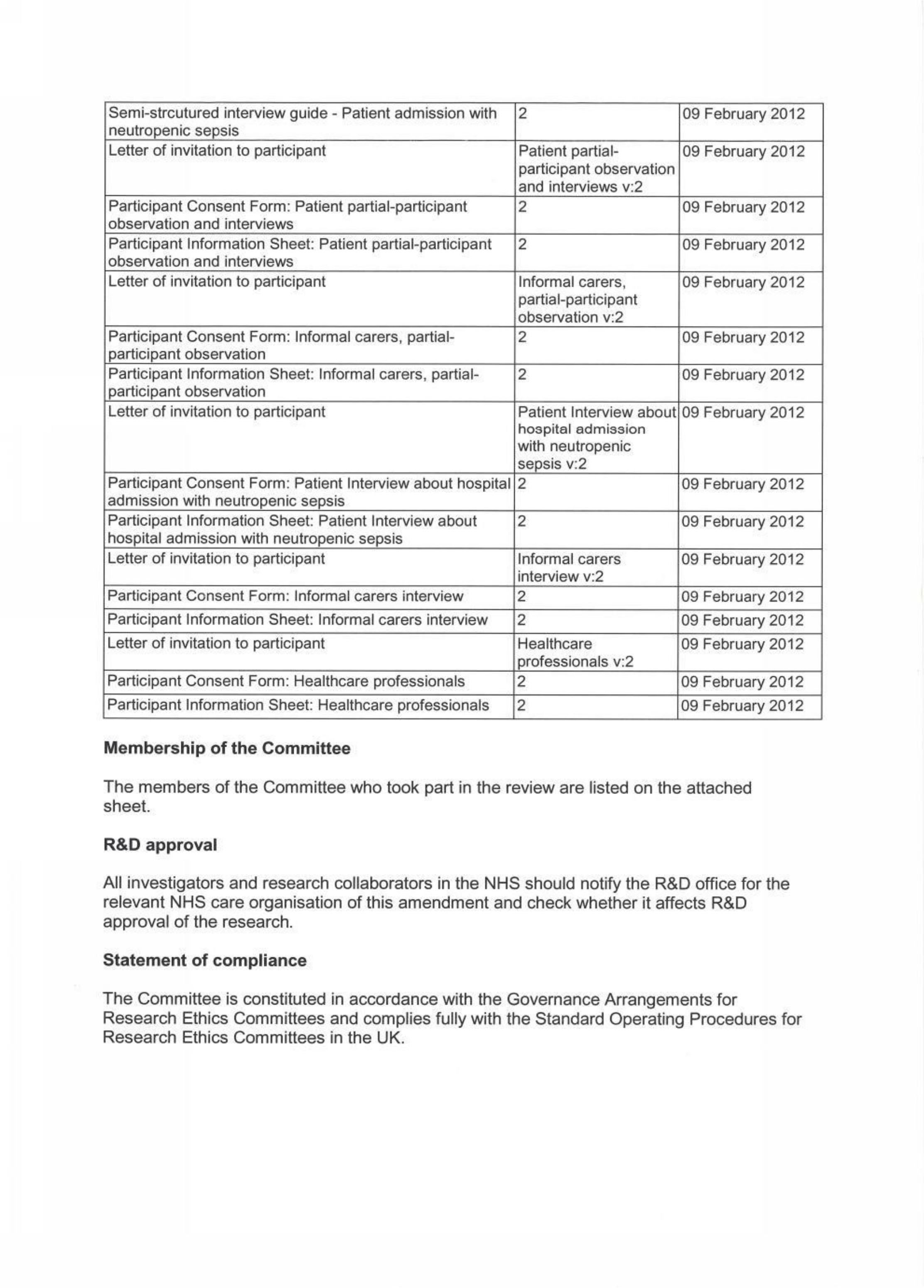
Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	Patient - Interview 1 v:2	09 February 2012
Protocol	2	09 February 2012
Notice of Substantial Amendment (non-CTIMPs)	02	13 February 2012
Interview Schedules/Topic Guides	Patient - Interview 2 v:2	09 February 2012
Interview Schedules/Topic Guides	Patient - Interview 3 v:2	09 March 2012
Demographic information	2	09 February 2012
Semi-structured interview guide - Healthcare Professionals	2	09 February 2012



Semi-strcutured interview guide - Patient admission with neutropenic sepsis	2	09 February 2012
Letter of invitation to participant	Patient partial-participant observation and interviews v:2	09 February 2012
Participant Consent Form: Patient partial-participant observation and interviews	2	09 February 2012
Participant Information Sheet: Patient partial-participant observation and interviews	2	09 February 2012
Letter of invitation to participant	Informal carers, partial-participant observation v:2	09 February 2012
Participant Consent Form: Informal carers, partial-participant observation	2	09 February 2012
Participant Information Sheet: Informal carers, partial-participant observation	2	09 February 2012
Letter of invitation to participant	Patient Interview about hospital admission with neutropenic sepsis v:2	09 February 2012
Participant Consent Form: Patient Interview about hospital admission with neutropenic sepsis	2	09 February 2012
Participant Information Sheet: Patient Interview about hospital admission with neutropenic sepsis	2	09 February 2012
Letter of invitation to participant	Informal carers interview v:2	09 February 2012
Participant Consent Form: Informal carers interview	2	09 February 2012
Participant Information Sheet: Informal carers interview	2	09 February 2012
Letter of invitation to participant	Healthcare professionals v:2	09 February 2012
Participant Consent Form: Healthcare professionals	2	09 February 2012
Participant Information Sheet: Healthcare professionals	2	09 February 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

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

Statement of compliance

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

11/LO/0488:	**Please quote this number on all correspondence**

Yours sincerely

Professor David Bartlett
Chair

E-mail: stephanie.hill7@imperial.nhs.uk

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

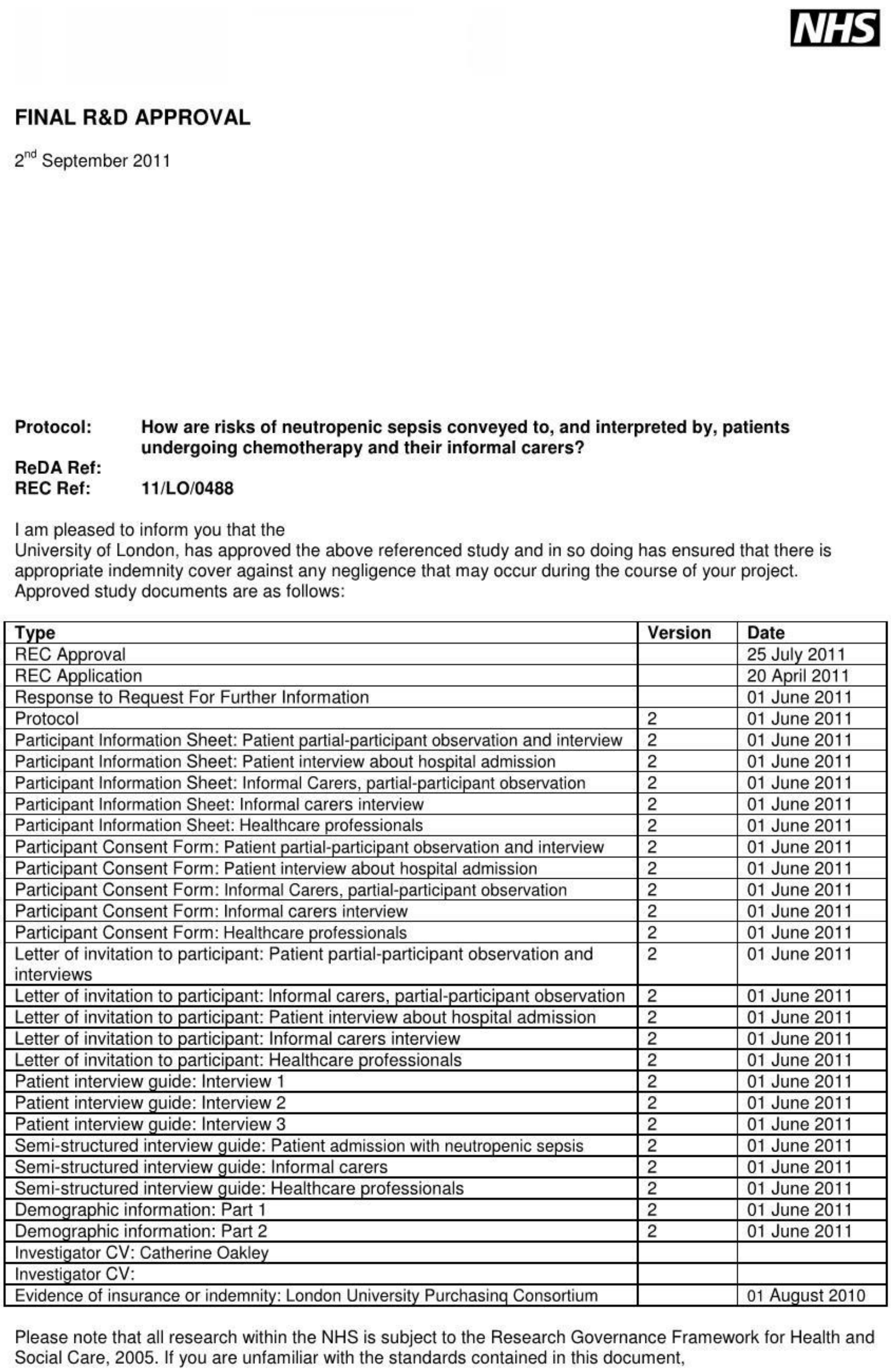
Copy to: *Keith Brennan, King's College London*

R&D Department, GSTFT

NRES Committee London - London Bridge

Members of the Sub-Committee of the REC meeting in correspondence

Name	*Profession*	*Capacity*
Professor David Bartlett	Honorary Consultant	Expert
Ms Karen Sanders	Senior Lecturer Nursing, Health Care Ethics & Law	Expert



FINAL R&D APPROVAL

2nd September 2011

Protocol: **How are risks of neutropenic sepsis conveyed to, and interpreted by, patients undergoing chemotherapy and their informal carers?**
ReDA Ref:
REC Ref: **11/LO/0488**

I am pleased to inform you that the
University of London, has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project. Approved study documents are as follows:

Type	Version	Date
REC Approval		25 July 2011
REC Application		20 April 2011
Response to Request For Further Information		01 June 2011
Protocol	2	01 June 2011
Participant Information Sheet: Patient partial-participant observation and interview	2	01 June 2011
Participant Information Sheet: Patient interview about hospital admission	2	01 June 2011
Participant Information Sheet: Informal Carers, partial-participant observation	2	01 June 2011
Participant Information Sheet: Informal carers interview	2	01 June 2011
Participant Information Sheet: Healthcare professionals	2	01 June 2011
Participant Consent Form: Patient partial-participant observation and interview	2	01 June 2011
Participant Consent Form: Patient interview about hospital admission	2	01 June 2011
Participant Consent Form: Informal Carers, partial-participant observation	2	01 June 2011
Participant Consent Form: Informal carers interview	2	01 June 2011
Participant Consent Form: Healthcare professionals	2	01 June 2011
Letter of invitation to participant: Patient partial-participant observation and interviews	2	01 June 2011
Letter of invitation to participant: Informal carers, partial-participant observation	2	01 June 2011
Letter of invitation to participant: Patient interview about hospital admission	2	01 June 2011
Letter of invitation to participant: Informal carers interview	2	01 June 2011
Letter of invitation to participant: Healthcare professionals	2	01 June 2011
Patient interview guide: Interview 1	2	01 June 2011
Patient interview guide: Interview 2	2	01 June 2011
Patient interview guide: Interview 3	2	01 June 2011
Semi-structured interview guide: Patient admission with neutropenic sepsis	2	01 June 2011
Semi-structured interview guide: Informal carers	2	01 June 2011
Semi-structured interview guide: Healthcare professionals	2	01 June 2011
Demographic information: Part 1	2	01 June 2011
Demographic information: Part 2	2	01 June 2011
Investigator CV: Catherine Oakley		
Investigator CV:		
Evidence of insurance or indemnity: London University Purchasing Consortium		01 August 2010

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, policies that reinforce them, you can obtain details from the Joint R&D Office or go to: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

You must stay in touch with the Joint R&D Office during the course of the research project, in particular:

- If there is a change of Principal Investigator
- When the project finishes
- If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any Serious Adverse Events (SAEs) or untoward events occur it is **essential** that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the

We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Copy to: Catherine Oakley, King's College London

Keith Brennan, King's College London

Appendix 5: Example of particpant information: Patient observation and Interview.

Florence Nightingale School of Nursing & Midwifery, King's College London. James Clerk Maxwell Building.1st Floor, Room 1.32. 57 Waterloo Road, SE1 8WA

catherine.oakley@kcl.ac.uk

Dear

Re: PhD Study: How is information about chemotherapy side effects received by patients undergoing chemotherapy and their carers?

I am a researcher from Kings College London University and am writing to ask if you may be willing to participate in my research study which aims to understand more about patients, carers and healthcare professionals' experiences of chemotherapy side effects. You are being invited to get involved in this research because you will be starting chemotherapy treatment in the near future.

I have provided a study information sheet with this letter which provides further details about my research and what this would mean for you, should you decide to take part. Essentially, this research would involve my attending two appointments with you and your carer (if applicable) where a doctor or nurse will provide you with information about your proposed chemotherapy treatment. I would then discuss the information provided with you and your carer. I would also like to carry out one audio recorded interview after your last treatment to discuss your experience of the chemotherapy.

If after reading this letter and the information sheet you decide you would like to find out more about the study I will be introduced to you by the doctor or nurse caring for you. If you decide you would rather not take part in the research your care will not be affected in any way.

Thank you very much for taking the time to read this letter and the information sheet.

Yours sincerely

Catherine Oakley (NIHR Research Fellow)

<u>Project Title:</u> **How is information about chemotherapy side effects received by, patients undergoing chemotherapy and their carers?**

You are being invited to take part in a research project. The following information will help you to decide if you would like to take part. Your participation in this project is voluntary. The researcher will be happy to answer any questions you have about the research so please do not hesitate to ask. Please take time to read this information and discuss it with your family if you wish, before deciding whether or not you wish to take part in the project. Thank you for reading this information.

Introduction

There is little research looking at how patients are prepared for chemotherapy treatment and its side effects. Researchers at Kings College London University are very interested in patients' experiences of chemotherapy information and are currently undertaking research in this area. The project involves patients starting chemotherapy treatment for breast cancer. If you are in agreement they would also like to involve the person who accompanies you to your hospital appointments in the research (your carer).

What the project is about

The purpose of this project is to understand the experience of cancer patients being treated with chemotherapy, their carers and healthcare professionals. In order to understand as much as possible about your experience a researcher will observe you and your carer (if applicable) contacts with healthcare professionals when you attend your first appointments. Then the researcher will ask you and your carer (if applicable) views on these meetings. Later, when you have finished your chemotherapy treatment, the researcher will interview you once to see how you got on with this.

Why have I been chosen to take part?

You have been chosen because the plan is for you to receive chemotherapy treatment for cancer at xx Hospital. A small number of people, around 20, like you will be invited to take part.

Do I have to take part?

You are under no obligation to take part in the research. If after reading this information sheet and discussing it with the researcher you decide not to take part, this is not a problem. If at any time during the project you decide that you no longer wish to take part please inform the researcher. This will not affect your care in any way.

What will happen during the study?

The researcher is based at Kings College London University London. Her name is Catherine Oakley. If you are interested in taking part in the study she will talk to you and your carer (if present) about it following your outpatient appointment today. The researcher will also provide an information sheet for you to pass onto the person you consider to be your carer. She will then telephone you in the next two to three days to discuss the project in more detail. The researcher will also ask you if your carer would like to participate in the study and will contact them separately to answer any questions they may have. If at that point you decide that you would like to participate in the study the researcher will arrange to meet you at your next outpatient appointment. There will be a further opportunity for you to ask questions at that time and if you still wish to participate the researcher will ask you to sign a consent form.

If you do take part in the study the researcher will be present during two of your chemotherapy consultations and will observe discussions you have with health professionals regarding your treatment. She will talk to you (and your carer if appropriate) about your time at the hospital and will make notes of her observations and conversations with you. With your permission the researcher will also digitally record the observed consultations and informal conversations. She will then interview you once to at the end of treatment. The interview will be carried out at a time and place convenient to you (home, hospital or over the telephone) and will last around 45 minutes. With your permission the interview will be audio recorded to allow the researcher to accurately remember what was discussed. If at any time you feel uncomfortable about being observed or interviewed you may ask for these to be stopped. If you are in agreement the researcher will ask you some additional questions about your ethnicity and social situation and will request permission to look in your medical notes.

What are the possible disadvantages of taking part?

You may feel uncomfortable about the researcher attending outpatient appointments with you. You may also find it difficult or upsetting to talk about issues related to your diagnosis of cancer and its treatment. You may also at times not feel well enough to be interviewed or that the time taken up is inconvenient. If this is the case the interview can be rescheduled or you may decide you no longer wish to take part in the study.

What are the benefits of taking part?

There are no direct benefits to taking part in the study although some patients find it comforting to have someone attend their appointments with them and to talk about their illness and treatment. It is also anticipated that this research will benefit patients in the future as the research results may lead to a change in practice.

What if there are any problems?

The researcher will raise any concerns regarding observed clinical care with the head of nursing. If you feel uncomfortable at any time during the research please ask the researcher to stop. If you would rather raise your concerns with someone else please do contact xxx, Head of Nursing for Cancer, at xxx Hospital on xxx.

Will my taking part in the project be kept confidential?

All information you provide during the research will be confidential. Quotes from conversations or interviews may be used in the final report and published papers to highlight the findings of the project. Your name will not be recorded on the notes used to write down the observations nor will it appear in any written report or talks given about the project. If you would like to receive a copy of the study when it is finished the researchers would be delighted to send this to you. Data will be stored for seven years on a secure data base by the university. Only the researcher and her supervisors will have access to the data. Recordings of interviews will be destroyed once data analysis is complete.

What will happen to results from the study?

Information you provide the researcher during informal or formal interviews will be used in the results section of the researchers PhD thesis. The research will also be published in cancer journals and presented at conferences, nationally and internationally

Who is organising and funding the project?

The project forms part of a PhD programme funded by the National Institute for Health Research. The research is being organised and carried out by a researcher, Catherine Oakley who is based at King's College London University.

Who has reviewed the research?

The research has been reviewed and commented on by the National Institute for Health Research (who are funding the research) and Professor XX and Dr XX who are experienced researchers. Professor XX and Dr XX are also supervising the project.

Contact point for further information

If you have any queries regarding the project do not hesitate to either contact: Catherine Oakley, NIHR, Research Fellow 07989659857 or xxxl, Head of Nursing for Cancer, at xxx Hospital on xxx.

Consent form (Patient, partial-participant observation and interview)

Project Title: How is information about chemotherapy side effects received by patients undergoing chemotherapy and their carers?

I confirm that I have read and understood the information sheet for the above research project.	☐
I understand that I am entering the project on my own free will and am free to withdraw at any time without my care being affected	☐
I am happy for the researcher to attend my chemotherapy consultations with me, to speak to me about my experience of these and to audio record the consultations and informal conversations	☐
I am happy for the researcher to interview me on one occasion and to audio record the interview	☐
I am happy for the researcher to ask me about my ethnicity and social status	☐
I confirm the researcher may access my hospital records	☐

------------------------------------ -------------------- -------------------------------

Name of Patient **Date** **Signature**

------------------------------------- -------------------- -------------------------------

Name of Researcher **Date** **Signature**

Taking Consent

Appendix 6: Example interview guides (January 2012)

Early Interview Guides

Semi-structured interview guide: Patient admission with neutropenic sepsis

Admission to hospital

- Can you tell me what happened from when you first became unwell and during your admission to hospital?
- What symptoms did you have and for how long?
- How long did you wait before calling the hospital?

Understanding of risk of neutropenic sepsis

- Could you tell me what you understand by a low white count?
- How much were you looking out for signs and symptoms of it?
- What do you think can happen to people with a low white count?
- How useful was the information you were given at the start of treatment in helping you to recognise the fact you had a low white count?
- What advice would you give a patient starting chemotherapy about looking out for a low white count and reporting this side effect to the hospital?

Semi-structured interview guide – Clinicians (February 2012)

Risk and conveyance of risk

- How much of a risk is neutropenic sepsis?
- How do you convey this risk to patients and carers? Do you treat any patient groups differently in terms of neutropenic sepsis risk information?
- How do you think patients and carers interpret the risk of neutropenic sepsis?
- How difficult or easy are these kinds of conversations to have with patients and carers?
- When should this kind of information be conveyed to patients and carers?
- Who should the information be conveyed to?
- How should the information be conveyed to patients and carers?

Experience of patient presentation

- What is your experience of patients presenting with neutropenic sepsis?
- Do patients with signs of neutropenic sepsis present in a timely fashion?
- Why do you think patients delay presentation?
- How does that make you feel?
- Whose responsibility is it to identify signs and symptoms of possible neutropenic sepsis?
- What do you think helps patients and carers recognise the symptoms of neutropenic sepsis and present early?
- Do you think we could do anything differently to help patients present early with neutropenic sepsis?

Examples of a later interview guide:

Doctor 2 (December 2012)

Introduction

- Introduce self and KCL.
- Introduce the study, who is it for, what is it about.
- Purpose of the interview.
- Length of interview.
- Voluntary nature of participation and right to withdraw.
- Reasons for recording the interview.
- Confidentiality and how findings will be reported.
- Any questions?

Icebreaker

- Explore experience of neutropenic sepsis and delays.
- Why do you think they delay?
- How do you feel when they delay?
- Any worse offenders?
- Any that present early?

Chemotherapy Information

- How do you explain neutropenic sepsis to patients?
- Do they ask any questions about it?
- Any patients you give different information too?
- Explore difficulty with giving same information? Standard repertoire.
- How well do they take information in? What stops them? What helps?
- What do they seem most concerned about?
- Do you think they read the information?
- Could you tell me a little bit about your workload and how you manage this or not ...

Presentation

- How do people typically present? What symptoms? TEMP
- Where do they present? Helpline, clinic, A&E
- What do they seem to know about it? How seriously do they seem to take it?
- How honest do you think they are about their symptoms and length of these?
- How easy or difficult do you think it is for patients and carers to recognise neutropenic sepsis symptoms?
- Do patients/carers ever argue about coming up? Or disagree with each other?
- Do you say anything different about neutropenic sepsis then?
- Explore experience of fast deterioration.
- What's it like when someone dies of neutropenic sepsis. How do the family react?

Liaising

- Do you get involved with arranging for review or admission elsewhere?
- How does that work? Any issues with that?

- Do you have a feel for the benefits of going to A&E or Oncology?
- Liaison with A&E and GP'S – How clued up do they appear about neutropenic sepsis?

Support

- Where do they get there support from? Who should support them through chemo?
- What role do you think carers play?
- How do patients and carers view the helpline?
- Do you know much about the pressures and priorities on the chemotherapy nurses?
- Would this impact on ability to support chemotherapy patients?
- Are the chemo nurses able to support the patients - symptom management?
- How well is the helpline managed – do they give the right advice?

Final

- Do you think that your perceptions of neutropenic sepsis differ to patients? How would you explain it to a colleague?
- I notice there is very little conversation about the risk of death with neutropenic sepsis?
- Is that your experience? Do you know why that might be?
- Do you mind me asking how you personally feel about having that type of conversation?
- Could anything be done to improve the service and early presentation?
- Any further thoughts on why patients delay?

Interview schedule for Alice following admission to hospital with neutropenic sepsis (November 2012)

- Introduce self and KCL.
- Introduce the study, who is it for, what is it about.
- Purpose of the interview.
- Length of interview.
- Voluntary nature of participation and right to withdraw.
- Reasons for recording the interview.
- Confidentiality and how findings will be reported.
- Any questions?
- Complete demographics.

Icebreaker **Ask to tell story leading up to admission to hospital.**

- What were you doing when it happened? Who were you with?

Explore Symptoms

- What sort of symptoms?
- How long?
- Getting better or worse?
- How much did they bother you?
- Fever - How did you know? Taking temperature? Wait until 38? Was it like any other illness e.g. flu?
- How quickly did you become unwell? Surprise? What imagined?

Calling for Help

- Trigger? Had you called before?
- Did you discuss with anyone whether to call?
- Did you look on the internet or in the chemo information? **BEFORE OR AFTER**
- Feelings about calling the hotline urgently? What's it for? Routine or emergency?
- What's it like calling that hotline?
    - How easy was it to get through?
    - Who did you speak to and what was said?
    - Did they know about you?
    - How quickly were you advised to get to the hospital with the infection?
    - Feelings about calling out of hours? Who prefer to call?
    - How would you feel about calling again?

Admission

- Feelings about going to hospital e.g. worried about waiting, infection, prefer to stay at home? Any concerns about possible chemo delay
- Any issues about getting there e.g. transport
- If been to A&E in the past, did you think it was necessary compared to other occasions?
- How ill did you think you were?
- Were they expecting you?
- What discussion did you have – e.g. Did you have to present your own case; did you show chemo card. Did you tell them everything – like being in bed unwell?
- How seriously did A&E take it?
- What was the care like? Was it what you expected? Liaison?

Chemotherapy Information at the Start

- Explore information sessions – tell me about
    - What sort of information were you given?

- How was it given?
- How easy was it to take in?
- What effect did the information have on you?
- What were you most worried about?
- What advice did they give you about other side effects?
- Was there anything you didn't like or didn't want to hear about?
- How felt about needing chemotherapy? Did you think you had a choice?
- Did the conversations about chemo make you think about the cancer more?
- How did feelings about starting chemotherapy compare to your diagnosis?

<u>Focusing on the low white count</u>

- Do you remember them talking to you about neutropenic sepsis or infection? (**WHAT DO THESE WORDS MEAN**) What is understanding?
- What key messages?
- Did you ask any questions?
- How much did you take in the information?
- How serious/important did the low white count seem to be?
- How ill did you think patients with neutropenic sepsis would be?
- How easy to treat did you think it was?
- Any idea about when you were most at risk?
- Did you think it would happen? Were you worried about it?
- Were you looking out for it? What symptoms?
- Did you plan ahead - think about what you would do if you got the symptoms?
- How were you told about looking out for neutropenic sepsis and calling? How did it make you feel? Do you think it encourages people to call (or resist)?

<u>Preventing Infection</u>

- How concerned were you about getting infection?
- Were you concerned about picking up infection in hospital?
- Did you think that getting an infection would be different for you?
- Patient/ family doing anything to protect against infection? Can you boost your immunity?
- Has normal/social life been affected by the infection risk?
- What effect did you think these sorts of things might have?

<u>What support is there for you?</u>

- Which doctor/nurse would you be inclined to contact? (Who is your key relationship with?).
- How would you describe your relationship with the hospital?
- Has the support from the breast team changed since starting chemotherapy?

<u>Normal Life</u>

- Explore how normal/work life was affected by the chemotherapy - other commitments?
- Did anyone go with you to information sessions? What was their role
- Involvement of friends and family. Change in relationships
- How feel about being reliant on others?
- Do you get advice from friends or family? How is this different to information from doctors or nurses?
- What do friends and family know about neutropenic sepsis?

<u>Making Decisions</u>

- Are you the sort of person who goes to the doctor?
- Any delay in cancer diagnosis?
- Who normally makes decisions in your relationship?

- Has memory, concentration/ability to make decisions changed since starting chemotherapy?

<u>Final</u>

- **Are you the sort of person who generally thinks I want to know every detail or do you tend to say I will wait and see what happens?**
- It's quite unusual but do you think you realised that people can die from this low white count?
- When people have this low white count, so reduced immunity, the earlier we treat it the better, the faster they recover from it and the longer it's left the more unwell people get? Risk of treatment delays. Do you think you and your family realised that?
- Do you remember the words used to describe the seriousness, e.g? Life threatening? What does that mean to you?
- I am interested in why people delay.
- What might delay patients?
- Do you understand something now that would help you to call earlier?
- Opinion on timing of information?
- Would talking to someone who had it help?

IF TIME READ OUT THE NEUTROPENIC SEPSIS INFORMATION AND ASK HER OPINION OF IT.

Appendix 7: Examples of NVIVO coding (allocated to PCC domains)

Phase 2 First 22 Data Sources
156 codes (initial)
13.7.12

Nodes

Name	Sources	References	Created On
Fostering Healing Relationships	0	0	19/04/2012
Playing down the seriousness - Skirting round the issue	14	50	10/04/2012 1
Taking on board messages from key individuals	13	26	23/04/2012 1
Recognisisng and Informing Riskier Patients	5	15	09/05/2012 1
Environment REMOVE	3	4	12/05/2012 1
They dont have enough time for me	11	29	13/05/2012 1
Forming relationships with healthcare professionals	9	21	13/05/2012 1
Instructiing and Obeying the Rules	16	69	14/05/2012 1
Taking an interest in my symptoms	4	4	28/05/2012 1
Researcher Effect	1	3	28/05/2012 1
Not engaging in conversations about serious side effects	1	3	23/07/2012 1
HCP not registering the seriousness or urgency	3	4	24/07/2012 1
Making a distinction between when it is OK or not OK to ca	10	28	25/07/2012 1
Waiting until a routine appointment	2	2	25/07/2012 1
Choosing to go to the GP	6	12	24/07/2012 1
Assessing the patient	2	3	25/07/2012 1
Not getting a response from hotline	3	7	25/07/2012 1
Accessing Encouraging to call the Hot line	17	48	25/07/2012 1
Preferring to call the Breast Care Nurses	7	23	25/07/2012 1
Having to present my case	7	11	25/07/2012 1
Going to the pharmacist	1	1	25/07/2012 1
Putting Faith in the Hands of Experts	9	30	25/07/2012 1
Scariness of not getting the right care	7	26	25/07/2012 1
Communicating about my care	11	25	26/07/2012 1
Personalising my information	5	7	26/07/2012 1
Lack of contact between treatments	4	6	26/07/2012 1
Delaying calling	8	20	30/07/2012 2
Negotiating, Accomodating	12	31	10/05/2012 1
Engaging with carers	4	8	31/07/2012 1
Treating me as a priority	1	2	03/08/2012 1
Arranging Support	1	1	03/08/2012 1
Subservient patient	1	3	06/08/2012 1
Developing a rapport	3	14	06/08/2012 1
Relieved to be getting away	1	1	06/08/2012 1
Identifying self with other patients	1	1	07/08/2012 1
Seeking to Reassure	2	4	07/08/2012 1
Providing Prophylaxis	2	4	07/08/2012 1
Being Honest About Side Effects	1	1	08/08/2012 1
Chemotherapy Nurses Explain Calling	1	1	08/08/2012 1
Empathy	1	3	08/08/2012 1
Exchanging Information	1	1	19/04/2012
Seeking out information	10	17	10/04/2012 1
Drumming it into me- it's their job	14	47	02/04/2012 1
Symptoms of NS	0	0	20/04/2012 1

Nodes

Name	Sources	References	Created On
Hard to believe it can happen so quickly	5	13	02/04/2012 14
Realising I had a temperature	10	50	02/04/2012 1
Feeling worse or better than led to believe	4	8	24/04/2012 11
Other symptoms are more Prominent	3	3	28/05/2012 14
⊟ Understanding	0	0	24/04/2012 1
Not making connection with symptoms and NS	10	24	24/04/2012 11
Infection - It's common knowledge that the chemo batt	14	70	02/04/2012 14
False sense of security	11	20	05/04/2012 1
Understanding the risky time	17	37	08/05/2012 11
Conveying the Earlier we Catch it the Better	13	39	28/05/2012 1
Vaguely remembering , not told, lost amongst other inf	7	17	23/07/2012 1
Taking in the information and asking questions	12	28	24/07/2012 1
Knowing what to do	8	14	25/07/2012 1
Conveying what happens after the phone call	16	37	27/07/2012 11
Detteriartion can be suprisngly fast	2	3	27/07/2012 1
Temperature may be early indicator	2	3	02/08/2012 1
Understanding would make me call earlier	1	1	06/08/2012 11
Checking Understanding	3	11	06/08/2012 1
Side effects are easy to manage	1	1	08/08/2012 1
Uncertain if patient will call	1	2	08/08/2012 1
Drip feeding- timing of information	15	40	09/05/2012 1
Information Overload- Overwhelming	15	33	15/05/2012 1
Standard Repertoire- going through the motions	11	32	15/05/2012 1
Grappling with a difficult concept	7	28	24/07/2012 1
Wanting to know everything	3	3	24/07/2012 1
The information is scary	5	9	26/07/2012 1
Being in the Chemotherapy - Ready to take it in	5	7	26/07/2012 1
Explaining the On-Call System	6	9	26/07/2012 1
Written information not important or underused	13	29	26/07/2012 1
Using Written Info to check symptoms	1	1	03/08/2012 1
Written information supporting verbal	4	8	03/08/2012 1
Focusing on infection	1	2	06/08/2012 1
Attempting to block further information	1	2	06/08/2012 1
Giving consistent messages	1	1	07/08/2012 1
Listening to Other Patients	1	3	08/08/2012 1
Giving the worse case scenario	1	1	08/08/2012 1
⊟ Responding to Emotions or Concerns	0	0	19/04/2012
Being Hit by the gravitiy of the situation	11	31	20/04/2012 0
Fatalistic-accepting what will be	7	22	20/04/2012 1
Fighting spirit- Staying Positive	6	8	20/04/2012 1
Protecting Others	7	10	04/05/2012 1
Low white count might delay my treatment	10	32	08/05/2012 1
Frustrating for healthcare professionals	6	20	09/05/2012 1
Backed into a corner- Resenting Poisonous Chemo	9	44	14/05/2012 1

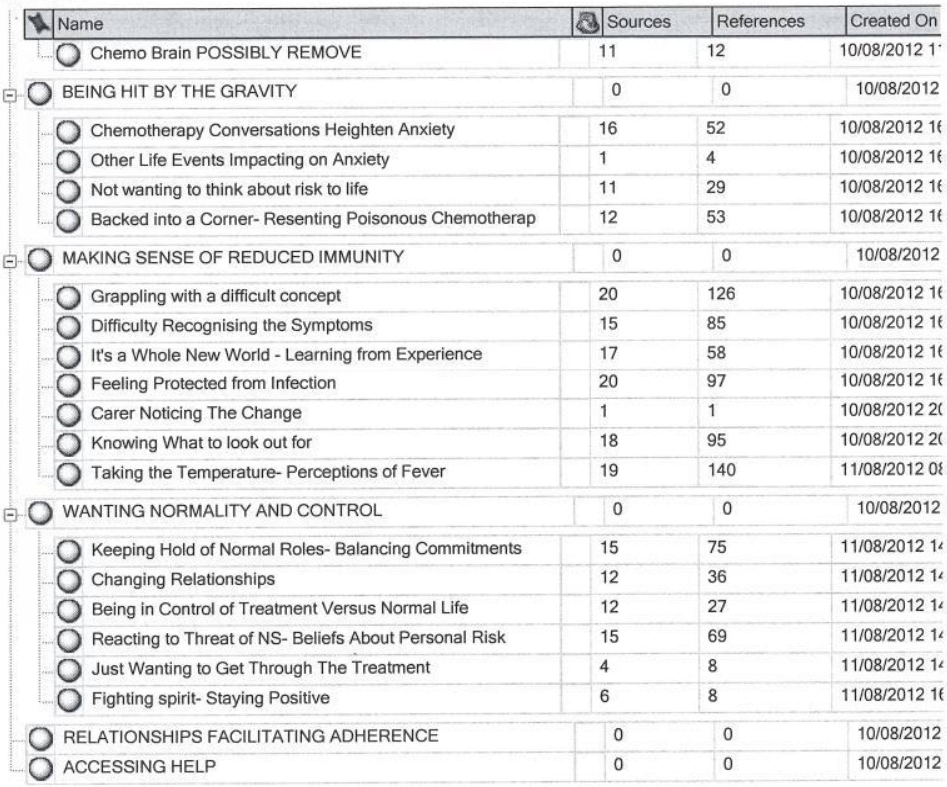
Nodes

Name	Sources	References	Created On
Not drawing attention	4	8	29/05/2012 1
Worried healthcare professionals	4	10	23/07/2012 1
Just want to get through it	4	8	23/07/2012 1
Wanting future episodes to be prevented	1	1	23/07/2012 1
Having to go to another hospital	11	14	23/07/2012 1
Discounting NSas a possibility	13	49	24/07/2012 1
Wanting Normality and Control over Life	8	34	24/07/2012 1
Not wanting to know about life threatening cancer and che	10	29	27/07/2012 1
Frightening to have to act straight away	3	6	27/07/2012 1
Fearing I might die	10	18	24/07/2012 1
Fearing the Drug Administration	5	16	27/07/2012 1
Worrying about preventing infection	7	8	24/07/2012 1
Focusing on Side Effects that Have Meaning	14	55	27/07/2012 1
Can't face further intervention	1	2	31/07/2012 1
Way of informing made me accept NS as a risk of chemoth	1	1	06/08/2012 1
Eliciting concerns	3	7	06/08/2012 1
No time to take it in	2	4	07/08/2012 1
Dealing with other life events	1	4	08/08/2012 1
Wanting the Chemotherapy	3	9	08/08/2012 1
Not wanting to depend on others	1	2	08/08/2012 1
Not knowing what to expect	1	1	08/08/2012 1
Worried about gettign a fever	1	1	08/08/2012 1
Managing Uncertainty	0	0	19/04/2012
Dealing with Unpredictable side effects	12	24	20/04/2012 1
Symptoms hard to recognise	13	42	24/04/2012 1
Bothering the helpline - Not crying wolf	14	47	05/04/2012 1
It's a Whole New World	6	14	04/05/2012 1
Striving to take control	1	2	25/07/2012 1
Taking control in normal life	1	3	25/07/2012 1
Dealing with cancer related uncertainty	1	1	03/08/2012 1
Explaining my personal risk	1	4	06/08/2012 1
Play it by ear	1	3	08/08/2012 1
Making Decisions	0	0	19/04/2012
Chemo Brain - affecting cognition	11	12	10/04/2012 1
Too ill - Weak, Delirious	4	11	19/04/2012 1
Taking a risk with getting infection	9	15	20/04/2012 1
Not inconveniencing Family or Friends- drawing attention	10	29	20/04/2012 1
Not wanting to go to hospital	11	24	05/04/2012 1
Getting away with it - take a chance	7	30	25/05/2012 1
Making Excuses- hoping it will pass	12	82	23/07/2012 1
Calling about symptoms that are important to me - trigger	11	83	23/07/2012 1
Not associating fever serious illness - normal temp manag	15	49	28/05/2012 1
Feeling better than before	1	2	26/07/2012 1
Waiting to call during the day	3	11	31/07/2012 1

Nodes

Name	Sources	References	Created On
Feeling too tired to go to hospital	3	3	01/08/2012 1
Didnt feel ill - thought I was OK	1	11	02/08/2012 1
I was getting better	1	2	02/08/2012 1
Enabling Self Management	0	0	19/04/2012
Carer Role	0	0	10/04/2012 1
Carers wanting to know how I can help	1	2	08/05/2012 1
Carers struggling with other commitments	6	8	08/05/2012 1
Carer & Patient Changing Roles & Relationship	3	5	08/05/2012 14
Carer Keeping me safe - all chipping in	11	24	10/05/2012 1
Carer, patient disagreement	5	9	23/07/2012 1
Carer telling what the patient doesnt want to mention	2	4	01/08/2012 1
Carer with patient at time of NS	2	3	02/08/2012 11
Carer noticing the change	7	17	03/08/2012 1
Care and Patient Working Together	8	25	03/08/2012 1
Responsible Patient	12	24	03/08/2012 14
Carer - Not wanting to be the one to cause ia problem	2	4	03/08/2012 14
Responsible Carer	8	23	03/08/2012 14
Carer Role During Information Session - Providing Mor	7	20	03/08/2012 14
Needing support of a woman	1	2	03/08/2012 1
Learning Through Experience- self or others	11	20	12/04/2012 1
Self monitoring Understanding what symptoms to look out	18	96	12/04/2012 1
Strategies to prevent infection	19	53	02/04/2012 1
Having Good Immunity Will Prevent Problems with NS	16	41	04/05/2012 1
Just get on with things-get on with normal life	9	29	13/04/2012 1
Priority placed on taking the temperature	16	42	24/07/2012 1
Knowing symptoms of fever	6	9	30/07/2012 1
Gettign to the hospital quickly	3	4	30/07/2012 1
Not masking the fever	1	1	03/08/2012 1
Preferring to stay at home	1	4	06/08/2012 1
Waiting to travel until after the chemo	1	1	06/08/2012 1
Equipping me to deal with it	1	1	06/08/2012 1
Knowing how to use a thermometer	1	1	06/08/2012 1
Planning to Manage Common Side Effects	2	6	08/08/2012 1
Understanding how ill people get	1	4	06/08/2012 1
Taking the temperature and Perceptions of Fever	0	0	10/08/2012 1
CONVEYING THE SERIOUSNESS	0	0	10/08/2012
Conveying the earlier we get it the better	16	58	10/08/2012 1
Repeating, drumming, ramming the message home	15	45	10/08/2012 1
Playing down the seriousness - Skirting Round the Issue	14	74	10/08/2012 1
Standard Repertoire - going through the motions	14	68	10/08/2012 1
Drip Feeding - Giving Information at the wrong time	19	112	10/08/2012 1
Overwhelming - information is lost	18	47	10/08/2012 1
Healthcare Professionals Worrying, Frustrated patients w	7	32	10/08/2012 1
Avoiding Scary Information	13	31	10/08/2012 1

Nodes

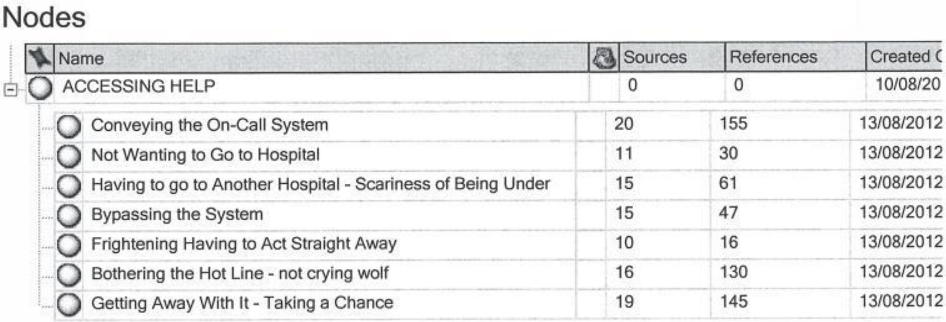


Name	Sources	References	Created On
Chemo Brain POSSIBLY REMOVE	11	12	10/08/2012 1
BEING HIT BY THE GRAVITY	0	0	10/08/2012
Chemotherapy Conversations Heighten Anxiety	16	52	10/08/2012 16
Other Life Events Impacting on Anxiety	1	4	10/08/2012 16
Not wanting to think about risk to life	11	29	10/08/2012 16
Backed into a Corner- Resenting Poisonous Chemotherap	12	53	10/08/2012 16
MAKING SENSE OF REDUCED IMMUNITY	0	0	10/08/2012
Grappling with a difficult concept	20	126	10/08/2012 16
Difficulty Recognising the Symptoms	15	85	10/08/2012 16
It's a Whole New World - Learning from Experience	17	58	10/08/2012 16
Feeling Protected from Infection	20	97	10/08/2012 16
Carer Noticing The Change	1	1	10/08/2012 20
Knowing What to look out for	18	95	10/08/2012 20
Taking the Temperature- Perceptions of Fever	19	140	11/08/2012 08
WANTING NORMALITY AND CONTROL	0	0	10/08/2012
Keeping Hold of Normal Roles- Balancing Commitments	15	75	11/08/2012 14
Changing Relationships	12	36	11/08/2012 14
Being in Control of Treatment Versus Normal Life	12	27	11/08/2012 14
Reacting to Threat of NS- Beliefs About Personal Risk	15	69	11/08/2012 14
Just Wanting to Get Through The Treatment	4	8	11/08/2012 14
Fighting spirit- Staying Positive	6	8	11/08/2012 16
RELATIONSHIPS FACILITATING ADHERENCE	0	0	10/08/2012
ACCESSING HELP	0	0	10/08/2012

Phase 3 First 22 Data sources
(focused coding) 41 codes
13.8.12

Nodes

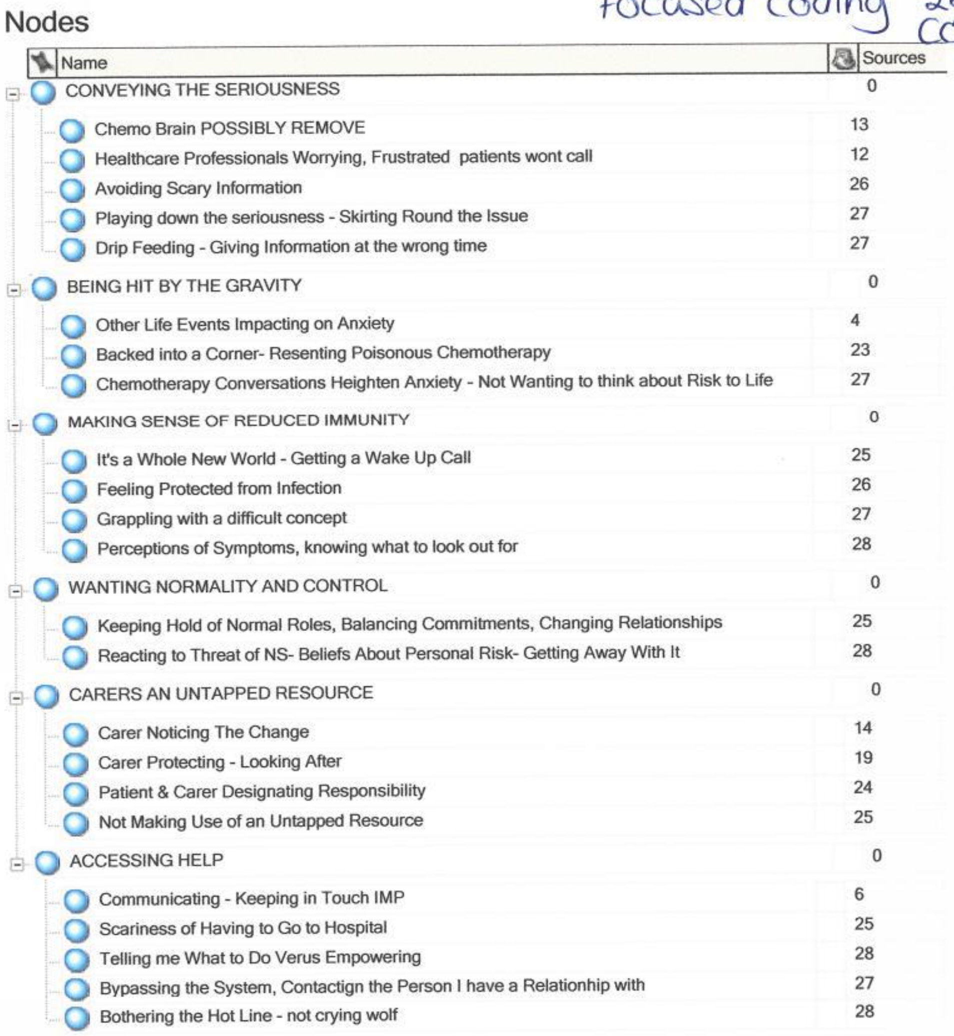
Name	Sources	References	Created (
CONVEYING THE SERIOUSNESS	0	0	10/08/20
Conveying the earlier we get it the better	16	58	10/08/2012
Repeating, drumming, ramming the message home	15	45	10/08/2012
Playing down the seriousness - Skirting Round the Issue	14	75	10/08/2012
Standard Repertoire - going through the motions	14	68	10/08/2012
Drip Feeding - Giving Information at the wrong time	19	112	10/08/2012
Overwhelming - information is lost	18	46	10/08/2012
Healthcare Professionals Worrying, Frustrated patients won	7	32	10/08/2012
Avoiding Scary Information	13	32	10/08/2012
Chemo Brain POSSIBLY REMOVE	11	12	10/08/2012
BEING HIT BY THE GRAVITY	0	0	10/08/20
Chemotherapy Conversations Heighten Anxiety	17	53	10/08/2012
Other Life Events Impacting on Anxiety	1	4	10/08/2012
Not wanting to think about risk to life	11	28	10/08/2012
Backed into a Corner- Resenting Poisonous Chemotherapy	12	56	10/08/2012
MAKING SENSE OF REDUCED IMMUNITY	0	0	10/08/20
Grappling with a difficult concept	20	125	10/08/2012
Difficulty Recognising the Symptoms	15	84	10/08/2012
It's a Whole New World - Learning from Experience	17	58	10/08/2012
Feeling Protected from Infection	20	98	10/08/2012
Carer Noticing The Change	1	1	10/08/2012
Knowing What to look out for	18	96	10/08/2012
Taking the Temperature- Perceptions of Fever	19	140	11/08/2012
WANTING NORMALITY AND CONTROL	0	0	10/08/20
Keeping Hold of Normal Roles- Balancing Commitments	15	75	11/08/2012
Changing Relationships	12	36	11/08/2012
Being in Control of Treatment Versus Normal Life	11	26	11/08/2012
Reacting to Threat of NS- Beliefs About Personal Risk	15	69	11/08/2012
Just Wanting to Get Through The Treatment	4	8	11/08/2012
Fighting spirit- Staying Positive	6	8	11/08/2012
RELATIONSHIPS FACILITATING ADHERENCE	0	0	10/08/20
CARERS	0	0	13/08/2012
Not Making Use of an Untapped Resource	8	26	13/08/2012
Carer Protecting - Looking After	11	27	13/08/2012
Patient & Carer Designating Responsibility	15	54	13/08/2012
HEALTHCARE PROFESSIONALS	0	0	13/08/2012
Negotiating Versus Instructing	18	95	13/08/2012
Developing Trust, Rapport - Caring About & Knowing M	18	108	13/08/2012
Enviroment not Conducive to Learning	0	0	13/08/2012
Engaging with Carers	6	10	13/08/2012
GAINING ADVICE OUTSIDE OF THE BREAST TEAM	14	30	13/08/2012



Nodes

Name	Sources	References	Created
ACCESSING HELP	0	0	10/08/20
Conveying the On-Call System	20	155	13/08/2012
Not Wanting to Go to Hospital	11	30	13/08/2012
Having to go to Another Hospital - Scariness of Being Under	15	61	13/08/2012
Bypassing the System	15	47	13/08/2012
Frightening Having to Act Straight Away	10	16	13/08/2012
Bothering the Hot Line - not crying wolf	16	130	13/08/2012
Getting Away With It - Taking a Chance	19	145	13/08/2012

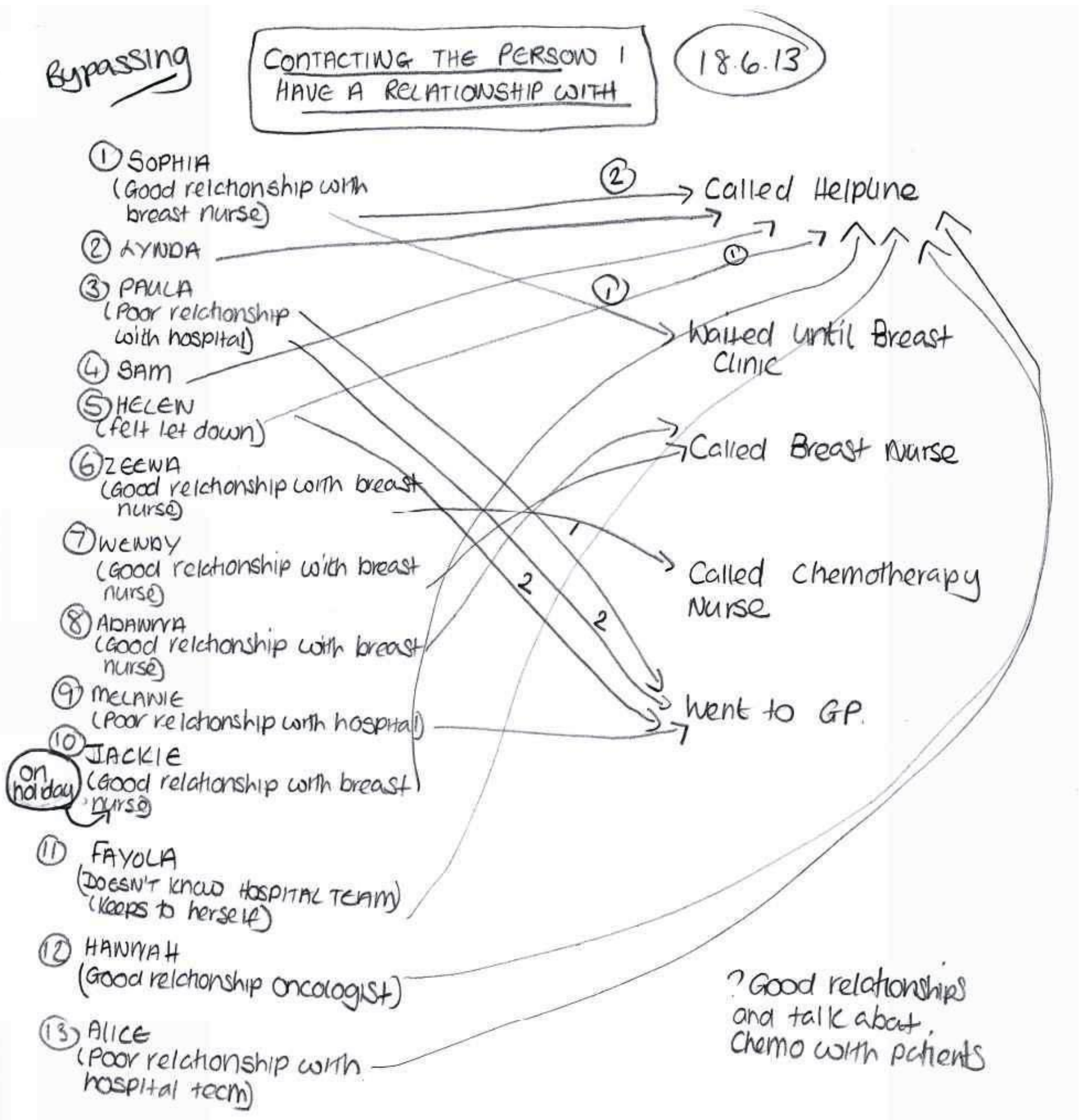
Phase 4
First 22 Data Sources
Focused coding 22 CODES.

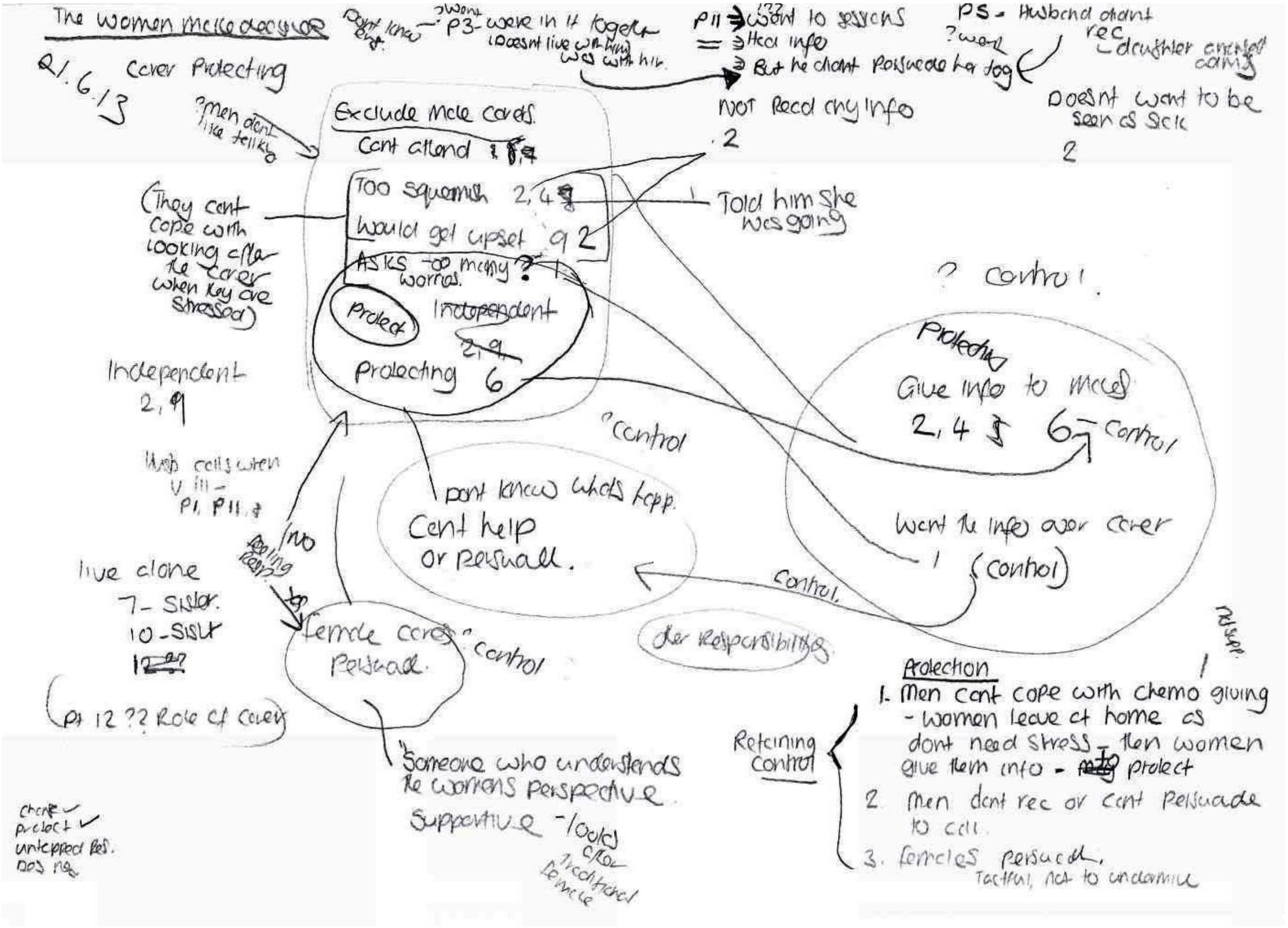


Nodes

Name	Sources
CONVEYING THE SERIOUSNESS	0
Chemo Brain POSSIBLY REMOVE	13
Healthcare Professionals Worrying, Frustrated patients wont call	12
Avoiding Scary Information	26
Playing down the seriousness - Skirting Round the Issue	27
Drip Feeding - Giving Information at the wrong time	27
BEING HIT BY THE GRAVITY	0
Other Life Events Impacting on Anxiety	4
Backed into a Corner- Resenting Poisonous Chemotherapy	23
Chemotherapy Conversations Heighten Anxiety - Not Wanting to think about Risk to Life	27
MAKING SENSE OF REDUCED IMMUNITY	0
It's a Whole New World - Getting a Wake Up Call	25
Feeling Protected from Infection	26
Grappling with a difficult concept	27
Perceptions of Symptoms, knowing what to look out for	28
WANTING NORMALITY AND CONTROL	0
Keeping Hold of Normal Roles, Balancing Commitments, Changing Relationships	25
Reacting to Threat of NS- Beliefs About Personal Risk- Getting Away With It	28
CARERS AN UNTAPPED RESOURCE	0
Carer Noticing The Change	14
Carer Protecting - Looking After	19
Patient & Carer Designating Responsibility	24
Not Making Use of an Untapped Resource	25
ACCESSING HELP	0
Communicating - Keeping in Touch IMP	6
Scariness of Having to Go to Hospital	25
Telling me What to Do Verus Empowering	28
Bypassing the System, Contactign the Person I have a Relationhip with	27
Bothering the Hot Line - not crying wolf	28

Appendix 8: Examples of analytical diagrams


Bypassing
CONTACTING THE PERSON I HAVE A RELATIONSHIP WITH
18.6.13
① SOPHIA (Good relationship with breast nurse)
② LYNDA
③ PAULA (Poor relationship with hospital)
④ SAM
⑤ HELEN (felt let down)
⑥ ZEENA (Good relationship with breast nurse)
⑦ WENDY (Good relationship with breast nurse)
⑧ ADANNA (Good relationship with breast nurse)
⑨ MELANIE (Poor relationship with hospital)
⑩ JACKIE (Good relationship with breast nurse)
on holiday
⑪ FAYOLA (DOESN'T KNOW HOSPITAL TEAM) (Keeps to herself)
⑫ HANNAH (Good relationship oncologist)
⑬ ALICE (Poor relationship with hospital team)
②
①
①
1
2
2
Called Helpline
Waited until Breast Clinic
Called Breast Nurse
Called Chemotherapy Nurse
Went to GP.
? Good relationships and talk about. Chemo with patients


The women male decision
Q1. 6. 13
Carer Protecting
? men dont like telling
Dont know ext.
? Wont
P3- were in it together
(Doesnt live with him) was with him.
P11 ⇒ ??? Went to sessions
= ⇒ Had info
⇒ But he didnt persuade her to go
Not Recd any info
2
P5 - Husband didnt rec
? work
- daughter arranged caring
Doesnt want to be seen as sick
2
Exclude male carers.
Cant attend ~~8~~,9
Too squeamish 2, 4 ~~8~~
Would get upset 9 2
Asks too many? worries.
1
Told him she was going
Protect
~~Independent~~
~~2, 9~~
Protecting 6
(They cant cope with looking after the carer when they are stressed)
Independent
2, 9
Husb calls when v ill -
P1, P11, 7
/no feeling Resp?
to
live alone
7- sister.
10-sister
~~12??~~
(Pt 12 ?? Role of carer)
? control
Dont know whats happ.
Cant help or persuade.
Female carers ? control
Persuade.
"Someone who understands the womans perspective.
Supportive - (older) ? Traditional female
? control.
Protecting
Give info to males
2, 4 ~~8~~ 6 - control
Went the info over carer
1 (control)
Control.
Other Responsibilities
Rel supp.
1
Retaining control
Protection
1. Men cant cope with chemo giving - women leave at home as dont need stress - then women give them info - ~~not~~ to protect
2. Men dont rec or cant persuade to call.
3. Females persuade. Tactful, not to undermine
Check ✓
Protect ✓
Unhelped Res.
Dos no


WANTING NORMALITY AND CONTROL
GETTING AWAY WITH IT 22/7/13.
IGNORING THE RISK
Piling on fear (No control)
(Ns Sounds frightening)
(cope) CONTROL
(cope) CONTROL
Take risk Seriously
· D2 told P8, P12
· partic who work in HC know what it is (Sophia/Mell partners)
Ignore Risk - T vision
P2 P1 P7 P12 P8 P10
(fat) 'ossassoc' Religion
Repeat pos
No planning ahead. -
· Reliant on carers with other commitments.
P4 waited for Hosp
+ Normality & control
· focus on Home/work
P11, 9, 10
Socially not putting p at P1
COPE
Cope
Focus on Prevent infection
(Some Repeated MC)
GWC Here
· physically fit
P1 9 2 8 10) (not in mc)
· Can avoid (Repeat)
· Carers Protective (dont want to be one to infect).
· Extreme precautions P7, C6 C2 P13
· Cant avoid infec so easily P4 (child)
P11 work took risk - work
* flexible working to manage infection risk. → wrong place. (Know timing (move to MC)
IGNORING SYMPTOMS (TU)
· All did this finished work P9, P11 - no pay
· HCP say pp made excuses
Keep checking temp
+ (But MC → unsure of SE).
· No one can bring me.
· Trying to make it go away.
P2 - Cool down
P11 - Lemsip
P7 - cold bath
P12 - fluids
P11, P9 → (finish work)
Social
- not drawing attention / making a fuss P1, P2 · Protecting P2, P6.
GETTING AWAY WITH IT
· Met pts appear to take greater risks 1, 3, 13 in favour of w/life.
· Repeat behaviour if get away esp met & P7 1, 3 → orcinas Dignt ask br re going away
Mentally / physically too ill to Act
REPEATED MC
GWC. Here
P2 4 6 12 - depressed as thought wouldnt happen.
? → MC
Reality Hitting
TO MC
· Not convinced serious / Exagerated P1, P7
Repeated MC - GWC
· Reality Hits during / after the event
Repeat pos
· found out at hosp P6, C11 P2
· looked on internet after P11, P5
· During interview P3, 13, 10

Appendix 9: Example of memo exerts to building up the core category: Playing down the seriousness and piling on the fear

Holding in the frustration		
Date	**Memo Title**	**Memo Exert**
22.8.12	Post CNS 1 Participant 1 observation and interview	Her information delivery style appeared quite forceful, possible due to her experience of patients not doing as they were told in reporting neutropenic sepsis. She appeared to find patients who delayed frustrating and talked about them suffering the consequences of not calling early enough. She feels she provides individual support. For high risk patients she hammers home the message. Clinicians seem to provide more information about neutropenic sepsis to non-compliant patients. She did not talk about any kind of discussion with patients about neutropenic sepsis. She recognised that patients don't want to bother us, but finds this odd. Neutropenic sepsis is a high profile symptom and is drummed into clinicians as something that is important, serious and should be looked out for. Need to talk to clinicians about how they view neutropenic sepsis and how they think patients and carers view it.
28.9.12	Clinicians worried and frustrated at patients non compliance	Clinicians consider that patient delay is a significant problem. They can't understand why patients delay presenting. They use the word DESPITE a lot; in terms of despite our instructing them to call they still delay. They really do feel they are doing their best for patients to get the message across. Use words like frustrating, disappointed, pissed off, annoyed, cross. I get a sense that clinicians think patients are instructed and therefore responsible. Patients are foolish (D1). Is there an element of blame? Explore. Good example with D1 where a GP spent a day trying to contact her. She felt the patient should have known better. Even where they think patients do understand they are not convinced they are going to call. Clinicians also use the word WORRIED a lot. They tell patients they worry about neutropenic sepsis – need to explore what they are worried about in more depth. Are they worried that they will be responsible if patients delay? They don't tell patients specifically why they worry. They say patients make excuses not to come up (e.g. childcare, no transport, nobody to bring them), don't want to bother the staff. This all points to patients not seeing neutropenic sepsis as important or a priority (ask patients what they would do if they had to go to A&E urgently about something else…Clinicians appear exasperated by this situation and don't know what else to do. What is the impact of clinician frustrations on communication with patients and carers about neutropenic sepsis?
09.02.13	Frustrated clinicians	Clinicians worry about patient delays in reporting neutropenic sepsis. They don't understand it and are frustrated by the delays. They are very concerned because patients can die from neutropenic sepsis and feel they do their very best to prepare patients to present early. This links to piling on the fear as it appears to cause clinicians to behave in a paternalistic way. They transfer a list of must do's to patients about recognising and reporting symptoms, sometimes scaring and telling patients off if they don't appear compliant or adhere to instructions.

(Appendix 9 continued)

Playing Down the Seriousness		
Date	**Memo Title**	**Memo Exert**
18.11.11	**Observation notes for Sophia**	No mention of risk of death. I wonder if this has been discussed before or if the patient knows it. Patient asks no questions about neutropenic sepsis. Why?
6.6.12	**Playing down the seriousness**	Participants' accounts suggest the seriousness of neutropenic sepsis is underplayed. Possible link to taking infectious precautions. LINK to realise after the event and what would have helped recognise. Some patients feel clinicians do not stress the seriousness. Although CNS 1 talks of scaring patients. How do clinicians feel about talking about the risk of death? What are the difficulties? Do patients recognise the seriousness and how do they feel about it? **Source of information** – How and when is the internet used in relation to neutropenic sepsis. What written information is made available and how is it used. Some patients check the internet when they develop symptoms of neutropenic sepsis. Is this the same for other patients? Patients refer to the chemotherapy record book but I am not sure how well it is used. Some patients didn't keep this with them. One patient said that neutropenic sepsis was not mentioned in the literature. Do other patients and carers think the same? How clear is it in the literature? Maybe caught up with not linking low WBC, neutropenic sepsis and infection risk. Do patients read the information? Ask them what they understand by written information about neutropenic sepsis. Read it to them.
30.8.12	**Talking about death**	Clinicians do not like talking about life threatening risks of neutropenic sepsis with patients. This is something I recognise from my own practice. Generally, they are concerned not to scare patients about something they may never get. Doctor 1 considers breast cancer patients are at very low risk of getting neutropenic sepsis and told me she doesn't labour risks of chemotherapy induced organ damage either, which are also rare in this patient group. Consequently, clinicians tend to skirt round the issue and do not fully disclose life threatening risks (D1, CNS2, and CNS3). Observed clinicians generally used words like its serious, we worry, you need to call us quickly when talking about neutropenic sepsis, rather than people can die from it.
13.11.12	**Talking about death**	I need to probe much deeper why there are no conversations/questions when life-threatening is mentioned? **Are we afraid that patients will refuse the treatment?**
27.11.12	**Telling and not telling**	Oncologists may not want to explain the risk of death for different reasons to nurses. Nurses may be concerned not to frighten, whereas Oncologists may in addition be worried about patients refusing chemotherapy. Doctor 1 mentioned a patient refusing to continue treatment after a neutropenic sepsis episode… I sense some patients don't believe clinicians and don't take it seriously – this may link to getting away with it.

(Appendix 9: continued)

Playing Down the Seriousness continued		
Date	**Memo Title**	**Memo Exert**
09.02.13	**Playing down the seriousness**	Clinicians don't want to tell and patients and carers don't want to hear about it. Seriousness is skirted around. Patients are told to report a high temperature urgently but there is no discussion and the reasons for this are not explored. Clinicians counteract scaring by underplaying, inferring it is unlikely to happen and easy to treat. Some patients are scared by the chemotherapy information and don't want to hear about neutropenic sepsis. They don't take it seriously or treat it as important – think clinicians are doing their job, but it won't happen. Clinicians treat those thought to be at high risk of not complying differently and attempt to **scare** them. Information is given in a negative way and benefits to the patients of attending early are not conveyed. The seriousness is recognised by some patients and carers once they have had neutropenic sepsis (making the connection).
Piling on the fear		
Date	**Memo Title**	**Memo Exert**
6.6.12	**Playing down the seriousness**	**Interacting/asking questions.** Extent to which questions are asked or encouraged to enable self management. There appears to be little interaction or opportunity to ask questions. Some patients don't want to ask questions – maybe they can't cope with any more information, maybe they feel they won't understand. Some clinicians invite patients to generally ask questions, but the offer is rarely taken up, so may not be encouraging a response or maybe patients are too overwhelmed to respond. What questions are asked by clinicians and patients/carers? What would they like to ask? How interactive are the conversations? Do patients and carers feel able to ask questions and to whom? **Standard Repertoire (the chemo chat)** – Information sessions appear scripted. Seems common and I recognise this from my own practice. Need to explore to what extent this is personalised and what is the effect of standard repertoire on patients? How do clinician participants find providing the same information to multiple patients? **Drumming it into me – it's their job** – Stressing and repeating information. Duty to transfer the information. CNS1 thinks scaring the patient and repeatedly stressing the information will get them to conform. Some patients say they were not told about neutropenic sepsis. To what extent is information reinforced? How does this make patients and carers feel and what effect does it have? In my previous research, clinicians felt they needed to transfer responsibility to the patient and this may be the case here? Is there something different about patients who felt they weren't told?
29.7.13	**Piling on the fear**	Clinician‘s frustrations about patient delays and reluctance to discuss neutropenic sepsis (Playing down the seriousness) emerged through their piling on the fear about infections rather than explaining neutropenic sepsis. This alongside the reality of starting chemotherapy may have affected patients' ability to take on board information about neutropenic sepsis, as fears about cancer and chemotherapy were heightened, especially for those who had metastatic disease (link reality hitting).

(Appendix 9: continued)

Reality hitting		
Date	**Memo Title**	**Memo Exert**
6.6.12	**Drip feeding-timing of information**	Information about neutropenic sepsis is provided when patients are trying to take in a cancer diagnosis. CNS 1 said information should be drip fed but patients said neutropenic sepsis was never mentioned after the initial chemo consultation...To what extent is information drip fed? When do patients want the information? When would they most benefit from the information? Amount of information given and effects of this. Some patients felt overwhelmed and frightened by the information. Many patients referred to not hearing the information. How much information are patients given? How do they attempt to process this or not? What is the effect? How much do they forget?
11.10.12	**Being hit by the gravity**	When patients attended chemotherapy information sessions, they hadn't got to grips with the cancer diagnosis. They were on a roller coaster (P10)...still shocked from the diagnosis (CNS3; D1) and threat to mortality and what that meant, what treatment was needed and the likely benefit. Information about neutropenic sepsis was given whilst these fears were present. Death was the fear for most (CNS3; P3). People perceive chemo as nasty stuff – so they come along with this baggage (D1). I think the seriousness or gravity of their situation seemed to hit people as they were repeatedly given information about serious chemotherapy side effects...basically neutropenic sepsis (P1). P1 felt frightened and out of control. P1 said...the information made her feel doom and gloom. During observations patients gradually appeared more anxious as information about nasty side effects was delivered. Observations were good here as patients couldn't always remember this afterwards...Patients indicated they did not like hearing scary information about neutropenic sepsis and knowing they had to call the helpline urgently with a temperature or you could be dead makes the seriousness of the cancer more real (P1; P7; P10). P3 taking the temp is a reminder of the illness. Does this affect people taking a temperature seriously or do they avoid thinking about it? Annotation P7 - This lady didn't like hearing about the temperature, the fact you need to call straight away and can die quickly. So she got the message but didn't want to hear it. ... How do people view the actual chemo treatment? Need to look at views about being given information in the day unit. How did they feel when they went in? P10 – during first chemo another patient collapsed… I wonder if there are differences with people who are in a more serious position. Patient 1 and P3 spring to mind – more appears invested in the chemotherapy.

(Appendix 9: continued)

Reality hitting		
Date	**Memo Title**	**Memo Exert**
(cont'd)		Conversations about chemotherapy side effects are given at the same time as discussions about prognosis and future treatments. With metastatic patients these other conversations may be more protracted and the focus is much more on will I live or die, so the need for chemo is more important /urgent and may detract from hearing information about chemotherapy side effects. P6 though was not palliative and was more worried about the cancer than the chemo. Ask patients how they felt about chemo and the cancer. Highly stressful situation and all these worries – means people can't take the information in (C2)**Avoidance** HCP – CNS1 try to scare some patients into taking on board the seriousness of neutropenic sepsis, but they are already scared **(How does scaring make patients and carers feel in context of the bigger picture)** Do some people avoid scary information more than others... (Getting Away with it). Indication by C2 that she is terrified of what someone is going to tell her– cancer is death sentence so anything that makes that more certain like neutropenic sepsis is avoided. How do people feel about hearing about life threatening risks of chemotherapy? CNS2 says patients don't want to hear it and look blank and maybe in denial and are afraid of hospital. But are people afraid of the chemo? P1 blocked out negative thoughts, the more she heard about side effects the more she didn't look for them. Struggles to realise its serious. Told me the reality was hard to take on board, tries to squash feelings she may feel like she is dying on chemo...Need to see if different people avoid or confront serious information. Look to see how others view heart damage – P12 I know did ask about it and P10 was also interested...P1 thinks chemo poisonous so between that and risk of infection makes it not great. Lots of negative information (P1). **Other Life events impacting.** I need to remember that patients and carers have other life events that might occupy them and impact on reporting. Patient 1 and carer 1 speak of a relative dying whilst the patient was going through chemotherapy...they both took risks in reporting infections... It must be difficult to make rationale and safe decisions when undergoing the stress of someone dying in another country. P10 too had recently lost her mother and I wonder what impact that might have on her ability to report...