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

Developing Interventions to Enable Healthcare Professionals to Meet the Needs of 'Carers' in the Chemotherapy Treatment Setting

A Participatory Research Study

Verity, Rebecca

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

Developing Interventions to Enable Healthcare Professionals to Meet the Needs of ‘Carers’ in the Chemotherapy Treatment Setting: A Participatory Research Study

‘Time to think about Carers’

Rebecca Verity

A Thesis Submitted to the University of London for the Degree of Doctor of Philosophy

Florence Nightingale School of Nursing and Midwifery

King’s College London

February 2015

This study has been supported by a Doctoral Fellowship Award from the National Institute of Health Research (NIHR).

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

Abstract

Background: Delivery of chemotherapy treatment in the last twenty years has shifted from inpatient to outpatient settings. Helping patients to manage adverse treatment effects has become the domain of family and friends (carers). A healthcare service and policy imperative was the need to provide carers with more support. Yet, service providers were unclear on how best to do this.

Overall Aim: To identify and develop interventions to enable healthcare professionals to prepare and support family and friends (carers) in the chemotherapy setting.

Methodology: An engaged scholarship and participatory approach underpinned by the initial iterative phases of the UK MRC (2000; 2008) Framework for Development and Evaluation of Complex Interventions. In the pre-clinical phase qualitative methods were used, including: participatory observation (>250 hours), in-depth interviews with healthcare professionals (n=22), carers (n=13) and patients (n=3) and two workshops. Action research underpinned the modelling phase.

Findings: Initial findings revealed that carers were not proactively prepared for the important roles they held; as a result they felt extremely uncertain and unsupported. Conversely, some carers' reported that what eventually helped them were individual skilled nurses who were mindful of their roles and needs, had the ability to acknowledge and manage difficulties, and sign-post people when necessary to other sources of support. However, most healthcare professionals did not address carers' needs in practice. Healthcare professionals were found to endure unrelenting workloads and worked within complex and constantly evolving clinical settings. Practitioners acknowledged that genuinely involving carers in these environments was difficult. Healthcare professionals described a reticence to engage with carers as '*avoiding opening the cans of worms*'. Explanations included: insufficient skills and confidence, particularly for managing difficult emotions and family dynamics, a lack of professional guidelines, organisation and team support, time and supportive care resources. Until now healthcare professionals' needs and numerous challenges to effectively support carers had been a neglected area in practice and research.

In the modelling phase nurses were encouraged to get off the '*hamster wheel of busyness*'. In doing so they identified and initiated numerous person-centred actions, for example, nurses, supported by a carer advisory group, developed tools for carers and changes were made to the environment and pre-chemotherapy consultations.

Conclusions: Through creating safe spaces and critical facilitation, nurses were enabled and found solutions to overcome some of the challenges they experienced when engaging with carers, by learning from role models and supporting each other. However, this research has demonstrated that if healthcare professionals are to fulfil the current political and NHS aspirations of person-centred care, which incorporates carers' needs, then they must have the practical guidance, support and resources to do so. An integrated approach, unifying policy, education, the organisation and multi-disciplinary team needs to be established.

Table of Contents

Table of Figures

Table of Tables

Acknowledgements

At the beginning of this study I intended to involve as many people as possible. Reasonably successful in this endeavour I now have a dilemma. I want to acknowledge and recognise everyone’s contribution. However, to thank individually by name the many people who participated and supported me in this work would fill many pages and in some cases jeopardise the promise of anonymity. So to everyone who helped me, the participants, advisors and colleagues, many of whom have become firm friends – thank you.

I must acknowledge my supervisors, Professor Alison Richardson for getting me going, being a mentor and believing I could do a PhD. Professor Emma Ream and Professor Sarah Cowell who supported the fellowship application and started me off on the journey. Special thanks to Professor Jackie Sturt and Professor Alison Metcalfe for supervising me over the last two years. Their wise words, enthusiasm, support and guidance got me through to the end. They helped me ‘feel safe’ in all the uncertainty.

I also want to thank all my family and friends for their enduring love, patience, encouragement and support, but especially Phil, Robert, Mum, Dad and Brian who will be deeply missed.

Glossary

Term	**Definition**
Action Research	A methodological approach, which has an explicit intention to involve others and enable change, through cycles of planning, acting, observing and reflecting.
Ambulatory Care	Healthcare treatment provided to patients without admitting them into hospital.
Capability	‘Extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance’ Fraser and Greenhalgh (2001, p.799).
Cancer Centres	A Cancer Centre is a designated regional facility either for oncology and/or haemato-oncology, also described as tertiary care and offers treatment for common cancers and rarer cancers.
Cancer Units	A Cancer Unit treats oncology and/or haemato-oncology patients and is usually part of a District General Hospital. Teams will work in collaboration with Cancer Centres.
Carers	People, usually relatives but sometimes friends, whom the patient identifies as providing significant unpaid support and care.
Carer Advisors	Members of the Carer Advisory Group.
Carer Advisory Group	An established group, whose members have had experience of supporting patients while having chemotherapy.
Carer Awareness	‘Being aware of and welcomes the valuable contribution carers can make and be mindful of carers’ own needs’ (Worthington et al, 2013).
Chemotherapy	In this study chemotherapy is defined as a toxic treatment (drugs) that prevents the growth and proliferation of cancer cells.
Chemotherapy Day Units	The outpatient department where chemotherapy treatments are administered.
Chemotherapy Nurse	A health professional, who provides nursing care to someone receiving chemotherapy.

Term	**Definition**
Clinical Guidelines	Advice aimed at practitioners based on the best available evidence and expert opinion.
Clinical Nurse Specialist	A nurse with specialist knowledge and advanced skills, who provides key worker support to the patient across the disease trajectory.
Competence	What individuals know or able to do in terms of knowledge, skills and attitude (Fraser and Greenhalgh, 2001, p. 799).
Consensus Meetings	Methods used for developing and establishing the collective opinions of a group – usually experts – when faced with uncertainty.
Emotions	Is a difficult concept to define, however, the definition used for the purpose of this thesis is *'organised responses, crossing the boundaries of many psychological subsystems, including the physiological, cognitive, motivational and experiential systems. Emotions typically arise in response to an event either internal or external, that has a positively or negatively valanced meaning for the individual'* (Salovey and Mayer 1999, p.186)
Emotional Awareness	Being aware of others' emotions, while also being aware of one's own.
Emotional Literacy	Asking the question: How are you? And be able and prepared to hear the answer.
Emotional Management	Acknowledging and managing others' emotions, while managing one's own.
Fieldwork	A collective term to describe the methods of data collection during the pre-clinical phase of the study.
Hawthorne Effect	The potential for the researcher to impact on or change participants behaviours as a result of introducing new concepts or from being observed.
Healthcare professionals	In this thesis the term healthcare professional has been used to describe all those who provide paid care to cancer patients in a formal professional context – terms such as clinician, practitioner, service providers are used interchangeably to describe these people, except when referring to an individual professional group e.g. nurses.

Term	**Definition**
Key Participants	These were nurses who were engaged and involved throughout the study and essentially acted as lead change agents.
Participatory Observation	A method of collecting data while observing and participating in the work of the research site.
Participatory Research	Participatory methodology has an explicit intention to involve others within the research.
Patient and Public Involvement (PPI)	Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for them’ (INVOVLE, 2012).
Primary Care	Usually the first point of contact for people accessing healthcare services provided by General Practitioners (GPs) and other community healthcare professionals.
Project Advisors	Members of the Project Advisory Group.
Project Advisory Group	An established group consisting of key stakeholders who had significant insight and expertise, either professional or personal, who provided guidance and support.
Reflexivity	The researcher accounts for their impact on the research setting, and acknowledges the impact on the researcher.
Stakeholder	People who have an interest in the project including research participants, other healthcare professionals, academic researchers and members of the public.
Supportive Care	This term encompasses all professional interventions, which aim to help patients and their families manage and live with cancer and its treatments.
Support Workers	These were staff members who worked in the cancer units and provided important administrative and clinical support. Although not professionally registered, they have been included under the umbrella term healthcare professionals.

List of Abbreviations

A&E	Accident and Emergency Department
AHP	Allied Healthcare professionals
BME	Black and minority ethnic groups
CAB	Citizens Advice Bureau
CDU	Chemotherapy Day Unit
CNS	Clinical Nurse Specialist
DH	Department of Health (UK)
GMC	General Medical Council
GP	General Practitioner
HNA	Holistic Needs Assessment
IRAS	Integrated Research Application System
MeSH	Medical Subject Headings
MDT	Multi-Disciplinary Team
MDM	Multi-Disciplinary Meetings
MRC	Medical Research Council (UK)
NCAT	National Cancer Action Team (DH)
NICE	UK National Institute for Clinical Excellence
NIHR	UK National Institute of Health Research
NMC	Nursing and Midwifery Council
Onc	Oncologist
PPI	Patient and Public Involvement
RCN	Royal College of Nursing (UK)
RCT	Randomised Control Trial
REC	Research Ethics Committee

Chapter 1 Introduction to Thesis

1.1 Introduction

This thesis reports a study which aimed to identify and develop interventions to enable healthcare professionals prepare and support family and friends (carers) in the chemotherapy setting. In this, the introduction chapter to the thesis, the rationale for this study will be established. Background information relating to cancer, chemotherapy and informal caring is presented. The overall structure of the thesis, including the aim, specific objectives and methodological approach is outlined. Finally this chapter provides professional and personal background information which aims to position me, as the researcher, within this study.

1.2 The Idea for the Study

The idea for the main focus of this research arose from a meeting held in the summer of 2008 with senior consultant cancer nursing colleagues from the regional cancer network and academics from the university. The aim of this meeting was to explore cancer nursing research priorities, based on the clinical challenges nurses were then experiencing. During this meeting the nurse consultants suggested there was an increasing need to enhance support for carers in the chemotherapy setting, but they were unclear how to do it.

In response to the senior nurses' concerns my academic colleagues and I submitted an application for a small research grant. The aim of this study was to explore the experiences and needs of carers in the chemotherapy setting using a mixed method approach (Ream et al 2008). The study provided the foundations for this PhD study and supported my application to the National Institute of Health Research (NIHR) Doctoral Research Fellowship (DRF) scheme. The findings from this small exploratory study revealed that carers were found to undertake important roles but had significant needs for support, which were rarely met (Ream et al 2010; 2013). We concluded that the needs of carers and how practitioners should intervene to meet these needs warranted further investigation. We agreed with Okamoto et al (2007) who recommended, in a report for Macmillan Cancer Support that the development and evaluation of interventions, which focused on providing supportive care for carers of cancer patients were urgently required (Macmillan 2007).

However, when writing the proposal to support the NIHR application, I had an increasing sense of unease, suspecting that developing feasible and useful interventions for carers was not going to be simple. For the application an indication of what form the intervention might take and how it could be delivered needed to be given. This was challenging. I questioned then whether we really understood the scope of the problems which needed to be addressed. I also doubted there was an easy solution to whatever these problems were. This uneasiness intensified when I considered I had witnessed throughout my nursing career many worthy healthcare research-based interventions either fail to be successfully translated into clinical practice or their use had not been sustained. These concerns greatly influenced the methodological approach undertaken in this research.

1.3 Complex Treatments for a Complex Disease

Cancer is complex, as a term it describes over two hundred different types of disease, all of which have different presentations and pathology (Palmieri et al, 2013). Currently it is estimated that there are two million people in the UK who have been diagnosed with cancer, with 300,000 new cases per year (Palmieri et al, 2013). This number will increase as more people continue to live longer and develop cancer in old age. Historically, most cancers had a short trajectory and inevitable mortality. Patient outcomes and disease-free survival rates have over the last twenty years significantly improved mainly due to enhanced diagnostics, delivery of services and advances in all treatment modalities. Many types of cancer are now considered a chronic disease (McCorkle et al, 2011). Extended survival, however, means that patients and their families are more likely to experience and have to live with the negative effects of the disease and its treatment for longer (Maher and McConnell, 2011; Morris and Thomas, 2001). Maintaining a good quality of life for cancer patients is steadily becoming as important as survival (Harrison et al, 2009; Macmillan 2008). While survival rates have improved, cancer remains a diagnosis that continues to evoke fear and distress in those it touches (King et al, 2006).

While cancer is a complex disease, so too is its treatment. Since the Calman-Hine report (DH, 1995b), which recommended a complete reorganisation of UK cancer services, nearly all treatment decisions are now made by multi-disciplinary teams (MDTs). Establishment of MDTs have since much enhanced complex treatment decisions and subsequently improved patient outcomes in the UK (DH, 2011). MDTs involve a diverse range of healthcare professionals and can include surgeons, oncologists, pathologists, radiologists, clinical nurse specialists (CNSs) and administration support staff (Simcock, 2013). Common cancers like breast and colorectal are usually treated by MDTs in local general hospitals, while patients with a rarer type of disease, for example, head and neck, are referred to a regional cancer centre MDT. However, teams across regions frequently work in collaboration, within cancer networks (Simcock, 2013).

Deciding which treatment a patient will have is determined by the type, stage and extent of disease, treatment intent, for example, whether it is for curative or palliative purposes, the patient's preference, age and fitness for treatment and the likelihood of treatment complications (Simcock, 2013). There are now five core treatment modalities including: surgery, radiotherapy, chemotherapy, endocrine therapy and a more recent addition, that of targeted and biological therapies. These treatment modalities are frequently given in combination. However, most patients will receive chemotherapy as part of their treatment plan.

Chemotherapy treatment is defined by Boothroyd and Lehoux (2004, p. x) as '*the administration of cytotoxic drugs that prevent the growth and proliferation of cells, and is especially used in cancer treatment in order to destroy neoplastic cells that show uncontrolled growth*'. Chemotherapy destroys or damages both cancer and normal cells. There are now more than 100 different types of chemotherapy, all classified according to their mode of action. These can be administered either as a single agent or more commonly as a combination of drugs (Skeel, 2007).

An improved understanding of how cancer cells grow and develop has exponentially increased and diversified the use of chemotherapy. It is now used with curative intent for a number of cancers including most haematological malignancies. Chemotherapy can be used in conjunction with other treatment modalities, for example, surgery. In this instance it is described as an adjuvant therapy. Alternatively, chemotherapy is employed as a 'cytostatic' therapy to control the growth of cancer cells in numerous malignant diseases (also called maintenance therapies). Chemotherapy is also used for palliation purposes to control symptoms, such as breathlessness, in patients with advanced disease. In these circumstances although not the intention, its use can result in extending the patient's life (Boothroyd and Lehoux, 2004). Typically patients now receive multiple courses of treatment over a protracted period of time (described as lines). While chemotherapy has greatly improved survival rates for many patients, it is a treatment that can significantly impact on patients' physical and emotional well-being (Mitchell, 2007).

Chemotherapy treatments are toxic, diverse and complex, and are often scheduled over weeks or months with some maintenance therapies lasting years (Colbourne, 2008). People undergoing chemotherapy have likened it to 'riding a physical and emotional roller-coaster' (Cowley et al 2000, p. 319). Every patient is different and each treatment experience will be unique. This is due to the unpredictable, fluctuating and severe nature of side effects associated with this treatment. Many patients can at times be extremely debilitated or become acutely unwell very quickly. Toxicities of chemotherapy can also accumulate and become more severe over the duration of treatment. Conversely, it is not unusual for some patients to feel physically well and independently care for themselves when they are receiving chemotherapy. The side effects, which typically arise at home and cause the most problems for patients and their families, include anorexia, nausea and vomiting, neutropenia and fatigue (Wilson et al, 2002). These side-effects are frequently under-reported by patients and thus under-treated (Molassiotis, 2008).

Consequently, these side-effects can impact considerably on patients' quality of life (Mitchell, 2007).

While the trajectory of the disease has shifted, so too has the delivery of cancer treatments from inpatient to ambulatory outpatient settings. Chemotherapy is now administered by nurses in chemotherapy day units (CDUs). As a treatment it can be administered via oral and systemic routes. A programme of chemotherapy is a planned period of repeated cycles of treatment. A cycle usually consists of one day of treatment, repeated every two or three weeks, over several months (Ockerby et al, 2012). An adjuvant course of treatment usually consists of six cycles. However, for some treatments (e.g. maintenance), chemotherapy can be well tolerated and cycles can continue indefinitely (Harper-Wynne and Kelly, 2013).

Although there have been significant improvements over the last decade in the management of chemotherapy toxicities, patients are at risk of experiencing debilitating side-effects and potentially life-threatening complications. Therefore, the downside of the shift from an inpatient to outpatient delivery service is that patients will have to manage the effects of both the disease and its treatment while at home; with limited access to knowledgeable healthcare professionals. Usually patients will only have contact with practitioners when their treatment is administered or in an emergency. The onus of managing adverse effects and disease symptoms at home and of reporting them to the healthcare team falls on the patient and their family or friends (carers). However, when patients are unwell, it is the carers who are increasingly responsible for making complex decisions about how to manage the adverse effects of treatment (Ream et al, 2010).

An important report which strengthened the motivation for conducting research in this area was published by The National Confidential Enquiry into Patient Outcomes and Death (NCEPOD, 2008). The findings of this report revealed that patients and carers delay seeking advice from healthcare professionals about chemotherapy-related side effects. This resulted in poor management of acute chemotherapy toxicity, such as neutropenic sepsis, and consequently led to poor patient outcomes and increased mortality (NCEPOD, 2008). It was not entirely clear why the delays occurred. Neither was it understood how patients and their carers came to decisions about the management of chemotherapy induced toxicities and what initiated or prevented the patient and carer alerting the healthcare professionals for support. This was a cause for concern.

In 2009 the National Cancer Action Team estimated that there had been a 25 per cent increase in cancer emergency inpatient hospital admissions since 2001 (NCAT, 2009). Many of these admissions were considered to be caused by an exponential increase in patients receiving chemotherapy and, therefore, more patients potentially experiencing toxicities requiring emergency medical attention. This trend is likely to continue as the numbers of patients treated is predicted to continue rising, with a year-on-year increase in the number of programmes of chemotherapy by around 15 per cent per annum (DH, 2010a). Inpatient cancer care is extremely expensive and accounted in 2009 for one half of the NHS cancer expenditure and 12 per cent of all acute inpatient emergency admissions (NCAT, 2009). Increased emergency admissions due to poor management of chemotherapy toxicities have therefore, serious financial implications especially in the current climate of economic challenges and reductions to NHS budgets. As a consequence of this and the findings of the NCEPOD (2008) report, the Department of Health's National Chemotherapy Advisory Team called for urgent improvements in the supportive care provided to patients who receive chemotherapy and to those who support the patient at home (NCAT, 2009).

1.4 What is Supportive Care?

An influential document at the beginning of this doctorate study was the NICE (2004) guidelines for improving supportive and palliative care for adults with cancer. This document outlined cancer services' supportive care priorities and the expected roles of different groups of healthcare professionals. In doing so it defined a vision for future cancer services, which in turn was to help inform clinical decision-making, establish targets and points of reference for the short and long term.

The working definition of supportive care, used by the NICE (2004) guidelines, is one suggested by National Council for Hospice and Specialist Palliative Care Services (NCHSPCS, 2002) and is professional caring that:

> *'…. helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment'.*

Supportive care is an 'umbrella term', and encompasses all professionally delivered interventions to manage physical symptoms and support psychosocial needs. Interventions can aim to provide emotional, practical and instrumental support. These can include strategies to enhance self-care, information giving and education, psychological support, counselling and symptom control, for example, analgesia for pain or exercise for fatigue (NICE, 2004). The NICE guidelines (2004) state that a wide range of service providers should be involved in delivering supportive care services to people with cancer. These include healthcare professionals from primary care, secondary care, voluntary and social sectors. The NICE (2004) guidelines state regardless of their professional background all healthcare professionals have a responsibility to ensure that patients and their families receive timely, supportive care. It was for this reason that all healthcare professionals, rather than one particular group, for example, nurses, were included as a focus at the beginning of this study.

The NICE (2004, p. 157) document clearly identifies that the needs of family and carers are considered, and specifically outlined two objectives for acute cancer service providers to aim for:

- Family members' and carers' needs are assessed, acknowledged and addressed.
- Carers have access to levels of practical and emotional support sufficient to enable them to fulfil the role of carer.

At the onset of this PhD study many of the NICE (2004) recommendations to improve supportive care for patients had been adopted by clinical practice. However, it was clear that the recommendations regarding families and carers, particularly in the acute treatment setting, had not been successfully translated into practice. NICE (2004) acknowledged that there were areas of 'uncertainty' related to the best models for delivering supportive care services. Unquestionably, supporting patients' family caregivers was one such area.

Harrison et al (2009) conducted a systematic review which aimed to determine the prevalence and consequences of unmet support needs of cancer patients at different points in the disease trajectory. These reviewers found that unmet supportive care needs can have a harmful effect on patients' and their families' well-being. Furthermore, patients had significant concerns, particularly during the treatment phase, regarding how those closest to them were coping. These concerns were not unfounded. Cancer patients' carers have been found, across the disease trajectory, to experience high levels of distress sometimes higher than that reported by the patient (Northouse et al, 1998, 2012; Pitceathly and Maguire, 2003). This distress could potentially prevent carers from caring (Adler and Page, 2008; Thomas et al, 2001). There is also evidence to suggest that caregivers are at risk from experiencing mental and physical health problems if their own needs are not addressed or they perceive themselves to be ill-equipped to care (Nijboer et al 1999; 1998; O'Mara, 2005; Grinyer, 2006).

1.5 What is a 'Carer'?

Defining what and who 'carers' are, is difficult. It will be seen in later chapters of this thesis that the terminology to describe those who support people while they were having chemotherapy has been a source of much debate throughout this study. When writing the proposal for this research the term 'informal carers' was used, which was then shortened to 'carers'. These terms were originally used for pragmatic reasons. Although it was recognised that many people who provide informal care dislike and reject being called a 'carer' (Heron, 1998), a better substitute could not be found which clearly and concisely described the patient's support person using just one word. Furthermore, since the 1995 Carers' (Recognitions and Services) Act (DH, 1995a; DH 1995c), 'carers' has become a term, which is frequently used by UK health and social services, policy-makers and researchers. Indeed, carers have been described by the Department of Health as someone who:

> *'Spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.'* (DH, 2008a, p.11)

The term 'carers' in this context describes the supportive role either a family member or others close to the patient can have. Thomas et al's (2001) comprehensive study was heavily drawn upon during the development of the NICE (2004) supportive care guidelines described above. This study in response to the Calman-Hine Report (DH, 1995b) aimed to explore how cancer services could best meet the supportive care needs of patients and their main carers. Thomas et al (2001) also described the difficulties of finding a suitable and acceptable term to use. Their description of the 'carer role' is the one operationalised within this doctorate study. They defined it as:

> *'The carer is that lay person whom a patient identifies as being in a close supportive role, and as 'sharing the most' in their illness experience' (*Thomas et al, 2001, p. 22).

In healthcare and social literature the term carer is often used interchangeably with terms such as family, friends, relatives, and spouse and significant other. Indeed Turner et al (2005) suggests there is often an assumption, especially made by healthcare professionals, that the 'family' is the provider of informal care. Defining the term 'family' is also difficult. Each individual has their own understanding of the term (Plant, 2008). Closeness in terms of living near or together and having an emotional connection, age, gender and culture impact on a patient's definition of who their family is, and who will be thought of as their primary carer (Brennan, 2004; Twigg and Atkin, 1994). People, who are family or friends, informally care within a context of '*love, duty and obligation'* (Twigg and Atkin, 1994; DH, 1995a). They undertake supportive care tasks '*beyond the normal reciprocities'* between adults (Twigg and Atkin, 1994, p.8). Informal caregiving is therefore a complex, frequently contentious and multi-dimensional concept involving personal, interpersonal and contextual factors and is usually culturally and politically shaped (James, 1994; Twigg and Atkin, 1994; Heron, 1998; Taylor, 2008).

1.6 Current Healthcare Provision and Carers in the UK

The general shift from inpatient to outpatient care in the UK was as a result of government policy which endorsed '*care in the community'* as a method for providing better care more cost-effectively (Twigg and Atkin, 1996). Consequently, the number of NHS hospital beds fell and there has been an overall reduction in the amount of time patients spend in hospital. The Royal College of Physicians (RCP) recently reported that there has been a 37 per cent overall increase in emergency admissions as a result of these changes (RCP, 2012). NHS organisations and staff working within them are under extreme pressures. Healthcare professionals are routinely experiencing problems and challenges seldom encountered twenty years ago. This is due to the rising costs of healthcare provision; a growing population, many of whom are living longer; rapid technological, medical and process innovations, higher consumer expectations and austerity cuts (Goodrich and Cornwell, 2008; RCP, 2012). At the same time there has been a significant shift in healthcare policy towards creating a NHS service which is more patient focused and responsive, rather than medically driven (DH, 2005b).

As a consequence of these significant changes and on-going challenges, the important role undertaken by carers in healthcare (not just in the cancer context) has become more widely recognised in the UK. This is reflected in national health and social care literature, policy and legislation (Nolan, 2001; DH, 2005a; DH, 2008b, DH, 2010c). It has also become an area of increasing concern. It is now understood that being a carer can come at a significant cost, (economically, physically and emotionally) to those doing the caring and to society (Carers UK, 2013). It is useful to understand who the carers are more generally in the UK, as this further explains why carers hold an increasingly important position within the UK health and social care systems and policy.

According to the 2001 National Census there was an estimated 5.7 million carers in England and Wales (Office of National Statistics 2001). Eighty per cent of these were likely to be immediate family members and 58 per cent were female. It was predicted that the number of people who provided informal care would continue to rise as more people are living longer and the population is getting older. Indeed this appears to be the case. In the 2011 National Census the number of people caring for a family member or friend who is ill, frail or disabled had risen by 11 per cent. There are now an estimated 6.5 million carers in the UK, of these 58 per cent (3.3 million) of people providing unpaid care were female and 47 per cent (2.7 million) were aged 45 to 64 (Office of National Statistics, 2012). Since 2001 there has been a 35 per cent increase in the number of carers over 64. It is predicted by 2037 that there will be nine million people who have caring responsibilities, many of these will be considered elderly and may have their own health problems (Carers UK, 2013).

In 1995 the Government established for the first time legislation relating to carers, in the ‘Carers (Recognition and Services) Bill’ (DH, 1995c). Consequently, carers had a legal right to request a 'carer assessment' from local authorities. It did not, however, establish in law how once assessed, carers' identified needs would be met or what the services should be expected to provide for carers. Since 1995, there has been further policy documents including the 1999 'National Strategy for Carers', which outlined a strategy for services to provide better information, support and care for carers, including the need to provide respite care (DH, 1999). In 2004 the 'Carers (Equal Opportunities) Act' ruled that local authorities had a duty to conduct a carer assessment, help carers to continue working or their education and seek ways to identify those considered to be 'hidden carers' (DH, 2005a). However, voluntary organisations, such as Carers UK, continued to lobby the government for better support from social and healthcare services. It was recognised that while legislation was in place, carers were frequently unaware of their entitlements and when they were would often struggle to ensure their rights were upheld (Carers UK, 2013).

In 2008 the White Paper, 'Carers at the Heart of 21st Century Families and Communities' highlighted the need for new strategies to recognise and value the role of informal carers (DH, 2008a). Subsequently in 2010 a policy document entitled, 'Recognised, Valued and Supported: Next Steps for the Carers Strategy', outlined how the Government would prioritise actions to ensure the best possible outcomes for carers and those they support (DH, 2010b). However, the Government is now once again reforming health and social care in the UK (DH, 2013). The 'Care Bill' determined that from 2015 people who provide informal care will no longer need to request an assessment from local authorities; carers should be routinely offered or referred for one by social and healthcare services (DH, 2013). Local authorities and healthcare services will have a duty to work together more coherently to provide services to support carers' identified needs (DH, 2013; Carers UK, 2013).

There have been estimates of how much carers are likely to save the UK NHS and social care system financially. Carers UK (2011), for example, suggested the economic value of the carers' contribution was as high as £119 billion. Many people, because of caregiving responsibilities, are unable to work. Although carers can currently claim benefits, for example, 'Carers Allowance', many do not. Carers were eligible for benefits if they provided at least 35 hours of support per week and did not earn more than £100 a week or were not in full-time education. In 2011 the carers' allowance was a paltry weekly payment of £53.09 (Reed, 2011). Plans were outlined to more readily establish those in financial need and increase the amount of benefit provided. This was to ensure that carers do not continue to find themselves in financial hardship as a result of caregiving (DH, 2010b). These plans have yet to be realised.

1.7 The Position of Cancer Carers in the UK

Most of these carer policy documents, which are outlined above, appear to focus on carers of physically disabled, dementia, stroke and mental health patients. They also acknowledged the needs of young carers. Cancer as a 'carer' issue was not mentioned. Yet, cancer patients and their families have been found to experience many challenges similar to those of other carers, created by the changes in healthcare delivery. Indeed patients and carers have reported 'feeling abandoned' by social and healthcare services when patients are at home (Macmillan, 2007, 2008). In response, Macmillan Cancer Support (Macmillan, 2011) and other cancer voluntary organisations, continue to exert increasing pressure on service providers and the government, lobbying for changes in policy in relation to cancer carers (Argyle, 2013).

Since starting this PhD study, a report published by Macmillan Cancer Support has estimated that there were in the UK approximately 1.1 million people aged over 15 who care for someone with cancer (Macmillan, 2011). They defined cancer carers as those who provide '*at least five hours of support a week or they give one to four hours and it affects their lives in some way'* (Macmillan, 2011, p.4). Sixty-two per cent of cancer carers were women. Although people of all ages provided care to cancer patients, the predominant age group was aged 45 to 64 (37 per cent). The characteristics of cancer carers were, therefore, similar to the profile of all those who provide informal care in the UK. It is estimated that currently two million people in the UK have been diagnosed with cancer. This number is expected to double by 2030 (Maddams et al, 2009). The numbers of those who become cancer carers, especially in the older age bracket, will also exponentially increase. Although, many carers met the current criteria for claiming the Carers Allowance, few cancer carers had received this benefit. Indeed very few had been offered a carer assessment (Macmillan, 2011).

While appearing to be ignored in 'carer' policy, policy makers have acknowledged and emphasised the important role of carers in cancer healthcare policy (DH 2010c, 2007; NICE, 2004; NCAT, 2009). In 2011 a policy document entitled 'Improving Outcomes: A Strategy for Cancer', established the Government's strategy for carers applies to people who care for cancer patients, as much as for carers of any other condition (DH, 2011). Cancer services now must endeavour to identify carers at an early stage, recognise the value of their contribution and involve carers from the outset, both in planning individual patient care and local service provision.

At the start of this study it appeared that cancer services were failing to meet the needs of carers in the acute treatment setting (NICE, 2004, Macmillan, 2011). When services did provide support it was often fragmented and reactive (NICE, 2004). There were wide gaps between what was advocated in healthcare policy (that carers' needs should be addressed) and how healthcare professionals responded to these needs. The reasons for this were not clear. Yet it seemed vital that healthcare professionals prepared and supported cancer patients' carers to enable them to support patients safely at home.

1.8 What was known about Carers in the Chemotherapy Setting?

To help develop the research proposal for this doctorate study, numerous searches of the following databases, including: CINAHL, Medline, PsycInfo, PubMed, Cochrane, DARE and Google Scholar were performed. These searches identified many papers of potential interest, including numerous literature reviews relating to carers (not just from the cancer setting) from health and social care, psychology and social science literature.

However, much of the research from the cancer field appeared to focus on the experiences and meeting the supportive care needs of carers in the palliative care setting. Harding et al (2004) and Hudson et al (2005, 2009), for example, developed, tested and evaluated psycho-educational interventions to support those who provided informal care to cancer patients dying at home. While these papers provided useful insights, arguably undergoing chemotherapy can create different challenges for patients and their families, which are unique to the acute treatment phase of the disease.

The searches, undertaken at that time, identified five research reports (Iconomou et al, 2001; McIlfatrick et al, 2006a; Schumacher, 1996; Tamayo et al 2010; Ream et al 2010; 2013), which focused specifically on the needs and experiences of carers during chemotherapy. Most of these studies had relatively small sample sizes and only two were conducted in the UK (McIlfatrick et al, 2006a; Ream et al, 2013). As previously discussed, Thomas et al (2001) also undertook a comprehensive study which aimed to explore the supportive care needs of patients and carers in all phases of the disease trajectory; the findings related to cancer carers were also reported in a separate paper (Morris and Thomas 2001). These studies provided some interesting insights.

McIlfatrick et al (2006a) in a small UK study explored caregivers' experiences of a day hospital chemotherapy service. Findings indicated that chemotherapy delivered in the outpatient setting allowed carers to '*hold on to normality*' as patients could remain at home while having treatment. However, some carers reported that it also created feelings of profound responsibility and anxiety. Further, while carers wanted to be included in the patients' experience of chemotherapy and viewed it as a shared process. Carers reported that they had received inadequate information about the adverse effects of treatment. Consequently, they felt unable to contribute to decisions about the patient's care. Thomas et al (2001) and Iconomou et al (2001) found carers experienced significant levels of emotional distress, reporting unmet informational needs as a major cause during the treatment phase. Conversely, Ream et al (2010, 2013) found that although carers' needs for information about treatment were mostly met; participants reported the quantity of information received was often overwhelming. These carers found it difficult to make sense of the information and what was pertinent to their own situation. Both Thomas et al (2001) and Ream et al (2013) found carers held an important role in helping patients make decisions about their treatment. Thomas et al (2001) emphasised the need for more relevant and accessible information, which would enable carers to be more involved when treatment decisions are made and subsequent care plans are developed.

As well as helping patients to process and understand the treatment information, Thomas et al (2001), McIlfatrick et al (2006) and Ream et al (2010, 2013) found that carers adopted other important roles during the chemotherapy phase including that of patient '*advocate*' and '*protector*', '*practical caregiver'* and '*symptom monitor'*. All these reports described the important role carers have helping patients to manage the emotional effects of the disease and treatment. Carers' roles were often unrecognised or underestimated by formal providers of care (Thomas, et al 2001; McIlfatrick et al, 2006 Ream et al, 2013). Carers had in all these studies significant needs, which remained unmet. Why this occurred was not entirely clear from the findings of these published reports. Most of the studies highlighted an urgent need for research-based interventions to prepare and support carers while patients are receiving chemotherapy (Iconomou et al, 2001; Schumacher, 1996; Tamayo et al 2010; Ream et al 2010; 2013).

Although numerous searches were performed, little published material was found, which explored healthcare professionals' experiences and needs in relation to supporting carers. Yet, it was envisaged that healthcare professionals could have significant challenges in knowing how best to support carers in the chemotherapy setting. Clinicians, for example, are not always clear whether carers are 'co-clients' or 'co-workers' (Morris and Thomas, 2001).

1.9 The Research Questions

The discussion above has provided the rationale for developing interventions, modelled on the identified needs of those who provide informal care for chemotherapy patients at home and those healthcare professionals who would deliver the interventions. Interventions aimed at enhancing carers' involvement, confidence and practical knowledge, and increase earlier reporting of important treatment side-effects were deemed vital. It was also apparent that research was necessary to raise awareness in healthcare professionals of carers and their needs from the onset of treatment, and identify strategies healthcare professionals could adopt to enhance the support they provided to carers. The overall research question at the beginning of this study, therefore, was as follows:

- How can healthcare professionals intervene to prepare and support carers of chemotherapy patients?

However, to obtain a comprehensive answer for this overarching research question required posing numerous questions while reviewing the literature and data collecting. Furthermore, at different points during the study further research questions revealed themselves, and these will be highlighted throughout the thesis. However, it should also be noted that the original research proposal aimed to develop interventions to prepare and support carers, this also subtly changed as the project evolved, although the objectives remained the same (see below).

1.10 Aims and Objectives of the Study

The overall aim of the study reported within this thesis, is as follows:

Overall Aim: To identify and develop interventions to enable healthcare professionals to prepare and support family and friends (carers) in the chemotherapy setting.

Specific Objectives

To meet the overall aim of the study this research initially had a number of specific objectives:

1. Describe how healthcare professionals currently prepare and support carers in the chemotherapy outpatient setting and identify any unmet needs.
2. Identify carers' perceived needs for role preparation, information and support, when supporting patients through chemotherapy.
3. Identify healthcare professionals' perceptions of carers' needs, how they perceive they should be addressed and their perceptions of the barriers and enablers to supporting carers.
4. Develop with healthcare professionals and carers, components of an intervention to prepare carers for, and sustain them in, their care-giving role.
5. Assess the feasibility and acceptability of the intervention/s.
6. Identify the training and support required by healthcare professionals to engage with and support carers.

1.11 The Research Design: An Overview

To meet the overall aim and objectives of this study, an engaged scholarship approach was adopted, underpinned by the initial two iterative, pre-clinical and modelling phases of the UK Medical Research Council (MRC, 2000; 2008) Framework for Development and Evaluation of Complex Interventions. The research design evolved throughout the study. The initial pre-clinical phase comprised of a qualitative, exploratory and increasingly participatory research design. While in the modelling phase, an action research approach was applied. An aim throughout this study was to involve those who would be the ‘end-users’ of the research-based intervention using various methods. The methodological approach is described and justified in Chapter 3. The specific methods used in the pre-clinical phase are described in Chapter 4.

1.12 Progressing Through the Thesis

In this thesis a conventional research reporting format is used. The exception is Chapter 7, in which both the methods and the subsequent findings from the modelling phase are presented. It should be noted that where-ever possible I have attempted to write about complex issues as simply as possible. I have also chosen to write in the first person throughout this thesis. This is because it is a predominately qualitative research study, which as will be seen in subsequent chapters was focused on changing practice. This type of research requires researchers to be critically reflexive and provide an account of their actions and their relationships with those that are being researched (Meyer, 1993a). Researchers need to position themselves within the study and acknowledge the potential for subjectivity and ownership of ideas, values and beliefs; reporting in the first person facilitates this (Jasper, 2005).

1.13 My Position within the Research

Throughout this doctorate study I have, as Cresswell (2009) recommends, given a lot of thought to the philosophical or worldview assumptions I hold. Worldviews or paradigms are defined by Guba (1990, p. 17) as a ‘*basic set of beliefs that guide action’*. Cresswell (2009) suggests these beliefs need to be made explicit. As the philosophical assumptions the researcher holds, and their previous professional and personal experience, may well influence every aspect of the research design, including what questions we ask and how we answer them (Denscombe, 2010).

If I had been asked before starting this doctoral study, which research paradigm I was most aligned to, I would have admitted that I did not particularly align myself to any. I thought I held a somewhat pragmatic worldview and that different research questions could be answered by different approaches and methods. Therefore, every methodological approach serves a purpose and has a value. The choice though depends on the type of question that needs to be answered (Ritchie and Lewis, 2003). However, as is expected when studying for a doctoral degree, undertaking this research has compelled me to consider and challenge these beliefs. In doing so I have had to unpick the hidden assumptions that I held regarding how we know and learn about the world in which we live (Cresswell, 2009).

1.13.1 Professional Background

The last twelve years of my career have been spent supporting and facilitating the learning of cancer healthcare professionals. Before starting this full-time doctorate study I was a lecturer in cancer nursing. In this role I delivered on various cancer education programmes, but had a particular interest in chemotherapy nursing. I also became in 2006 an advanced communication skills facilitator for Connected, a national programme established by the National Cancer Action Team (NCAT, 2013). Before moving into academia nine years ago, I held a position as a professional development facilitator within a NHS Trust, which specialised in cancer care.

Throughout my career I have believed that understanding health professional experiences and supporting their needs is essential if we are to improve the patient and carer/family experience. This belief and subsequently my professional interests have been shaped by a conversation I had in the late 1990s with a senior colleague, Sue[1]. I was then a junior sister, on a small haematology unit, based in a general district hospital. Sue was a haematology clinical nurse specialist (CNS). She was a nursing innovator and role model and was, for example, inserting intravenous (IV) access devices and administering chemotherapy, a long time before this had become a recognised, extended nursing role.

At that time within this particular hospital, chemotherapy administration was predominately a medical role. However, in reality the task of administering this treatment if Sue was not available was usually left to junior doctors. If patients required treatment they would have to wait for a junior doctor to come to the ward, to insert an IV device and start the chemotherapy. This would not be a priority task for the medical staff. Consequently, chemotherapy would start late in the evening or during the night. I was frustrated by this practice and believed if nurses working on the ward did this task, patients would receive their treatment more safely during the day. Further, adverse reactions would be managed swiftly because more nursing and medical staff would be available. Patients would also be less disturbed at night and have an overall better experience.

Sue agreed to teach me the intravenous skills she had acquired, which would enable me to administer chemotherapy to our patients. I told her I was really excited and could not wait to start. However, her response to my then naive enthusiasm shocked me. She told me "*you should be careful what you wish for*". She described a female patient who, when Sue had entered her room, had started to scream abuse at her. This patient blamed Sue for giving her horrendous

---

[1] Sue is a pseudonym

side-effects of treatment, which had made her very unwell and depressed for days. Sue told me that this experience had upset her greatly. She reminded me that chemotherapy was a toxic and aggressive treatment for patients to undergo. In effect I would be giving treatment to patients that would make them feel very ill. Sue challenged me, by asking "*how would you deal with that*?" This question changed the course of my career.

Sometime after this conversation Sue and I enrolled on a Masters (MSc) in Advanced Cancer Nursing programme. In the first year of the MSc, we both changed our roles and went to work at a large, renowned cancer centre. It was here that I first experienced chemotherapy being administered by nurses to patients, in both an inpatient and outpatient setting. Arriving at this specialist centre, I asked if there were any formal educational opportunities to increase my knowledge about chemotherapy. I was informed that there was not a course nor did I need one to work in this area. The lead cancer nurse suggested, *"you work here now, which is all the education you require for this role"*.

1.13.2 Previous Research: Chemotherapy Nurses

For my MSc research study, I decided to explore the experiences, attitudes and educational preparation of nurses who administer chemotherapy (Verity, 2002). I developed and used an exploratory survey design, which was sent to 260 nurses working within a specialist cancer hospital. The response rate was 39 per cent. The findings revealed that nurses were not well prepared for this role. As a consequence these nurses felt nervous and even scared when they first started administering chemotherapy. With increased experience, nurses reported gaining a positive attitude towards this task, especially if they had received further education and support from a knowledgeable role model. They continued to have concerns about various safety aspects of this role, for example, extravasation and risk of exposure. However, what experienced chemotherapy nurses appeared to worry about most was the practice of other nurses, their colleagues. Very few appeared to have difficulties or worries about providing information and emotional support to patients (n= 8) or their relatives (n= 12).

When I changed my role and came to work within an academic institution, the findings from the MSc study provided the foundations for ensuing research and teaching endeavours. Research using a postal survey design, based on the questionnaire developed for the MSc, revealed similar findings (Verity et al 2008; Wiseman et al, 2005). The survey questionnaire was sent to 526 chemotherapy nurses across 26 London hospitals providing cancer services, 257 replied (response rate 49 per cent). Many of these nurses had felt underprepared for this role. Although most reported experience, gaining more knowledge and having support from experienced role models had a positive effect on their attitudes towards chemotherapy. However, a significant number of nurses either strongly agreed (n =31) or agreed (n=117) to feeling distressed when they saw patients affected by the chemotherapy they had administered. Many of the chemotherapy nurses agreed (n=150) or strongly agreed (n=31) with the statement, *'it is easy to inform patients about their treatment but harder to help them emotionally'*. While 20 per cent of the sample (n=51) reported they had significant concerns regarding how they supported the patient's relatives, with 45 per cent (n= 117) occasionally finding this a worrying aspect of their work. What was not clear from these findings, was why this was the case and what would help nurses to overcome these concerns. However, nurses who had less experience and education worried more about being able to support the information and emotional needs of patients and their relatives (Wiseman et al, 2005). The overall conclusion was that nurses must be educationally prepared before undertaking this role and subsequently, have access to on-going development and support.

Consequently, the research described above influenced and instigated the development of different chemotherapy educational initiatives, including chemotherapy degree level modules and hosting national master class events for experienced nurses. Since this research began the role of the chemotherapy nurse has come under increasing scrutiny, mainly due to the exponential increase in the numbers of patients receiving chemotherapy. The role is defined by the Department of Health's National Cancer Action Team as *'essential to ensuring patients receive their treatment safely and effectively. This includes the safe delivery of the cytotoxic drugs and also providing patients with advice, education and support to ensure that the risks and toxicities are minimised. Chemotherapy nurses also ensure assessment and care planning for patients' wider holistic needs and improve the patient experience of the service provided'* (NCAT 2012, p. 4).

At the beginning of this chapter, it was described how the idea for the focus of this research resulted from a meeting with senior nurses at the regional cancer centre. I was somewhat perplexed by their suggestion that carers had unmet support needs, but not surprised. As a provider of chemotherapy education I was aware that nurses were taught about cancer patients' and their families' supportive care needs. Yet, there seemingly remained significant gaps between nurses' education and the current work of nurses in clinical practice. As a nurse I also understood that a core underpinning principle of nursing, (especially within the cancer domain), is to provide collaborative, supportive care to not only the patient but also their families (NMC, 2008; NICE, 2004).The puzzle, at that time, was why there appeared to be a disparity between an espoused nursing value and the actions of nurses in practice. In light of the discussion above, it is perhaps not surprising that exploring healthcare professionals' perspectives and experiences of supporting carers in this setting was deemed vital.

1.13.3 Personal Experiences of Caring

My worldview is also shaped by the roles I have in my personal life. I am a daughter, wife, mother, sibling, niece and friend. I have in these roles supported people through illness and disability. My now adult son for example, has learning difficulties and although reasonably independent, still requires a lot of support. Poignantly, both my parents were diagnosed with cancer during the early stages of my PhD studies. In the last six months of the fellowship period, while writing this thesis, my step-father suffered a catastrophic stroke. These experiences have without doubt profoundly influenced my beliefs of informal and professional caring and how the research was conducted.

1.14 Chapter Summary

This chapter has outlined the rationale for undertaking this research, which aimed to develop interventions to enable healthcare professionals to prepare and support people who informally care for those who are undergoing chemotherapy treatment. Background information relating to cancer care and informal caregiving has been provided. It can be seen that the landscapes for both continue to evolve and are extremely complex in nature.

In this chapter, I have also endeavoured to position myself within this research. I have indicated when starting this study that I was unsure where this PhD journey was going to lead me. I did not know what the interventions would comprise nor did I fully appreciate what the problems were that the interventions would aim to address. Although I had some ideas, I was not entirely sure how best to develop the intervention. However, I was fairly certain that it would be complex. I was also resolute that I would need to engage with others, those who would be the ‘end-users’ of the intervention. What I did not anticipate was the importance of building relationships with the people I met along the way. This thesis endeavours to tell the story of that journey.

Chapter 2 Carers in the Chemotherapy Setting: A Review of Reviews

2.1 Introduction

In this chapter the research evidence of carers' experiences and needs, and how healthcare professionals could potentially intervene to address these needs during chemotherapy treatment is examined. To explore these issues, a review of pre-existing reviews was undertaken.

The Medical Research Council (MRC, 2008) recommends, when developing complex interventions, the process should ideally begin with a systematic review to determine the scope and nature of the problem and identify what is already known about previously developed interventions. Conducting a review should help establish a theoretical understanding of the rationale for developing the intervention, what the intervention aims to change and how this can be achieved. The MRC (2008, p. 9) suggests '*you may be lucky and find a recent high quality review that is relevant to your intervention, but it is more likely that you will have to conduct one yourself'.*

As identified in Chapter 1, a preliminary search of a number of data bases was conducted, including: CINAHL, Medline, PsycInfo, PubMed, Cochrane, DARE and Google Scholar. The aim of which was to obtain a sense of the current literature relating to carers in the cancer setting and to help write the proposal for this study. A scarcity of research was identified that focused on carers' experiences and needs while supporting people having chemotherapy. However, a significant number of literature reviews were found that focused on informal caregiving more generally across the cancer trajectory. It was thought that a synthesis of these reviews could potentially 'tease out' findings pertinent to the chemotherapy treatment phase. The MRC (2008) recommends that a comprehensive review of the literature should always be undertaken before proceeding to a full-scale systematic review (meta-analysis) of interventions. Therefore, the overall aim of this review of pre-existing reviews was to inform the PhD study, by scoping or mapping the extent, range, quality and nature of research activity in this field.

2.1.1 Review Questions

This review of reviews endeavoured to answer these questions:

1. What are the extent, range, quality and nature of research activities regarding carers in the acute cancer treatment setting?

2. What are the experiences, roles and needs of carers in the chemotherapy treatment setting?

3. How can healthcare professionals intervene to support carers of chemotherapy patients?

2.1.2 Review Objectives:

This review has:

- Summarised review findings including: type and quality of studies, key findings and recommendations, gaps and limitations in the research.
- Explored the terms used to describe carers in the research literature.
- Explored if and what theory is used to underpin research in this area.
- Identified research gaps in the existing literature.
- Assessed the quality of pre-existing reviews using a researcher developed tool.
- Determined whether conducting a further systematic review (meta-analysis), of research-based interventions developed for carers, would be viable and beneficial for this PhD study.

2.2 Review Methodology

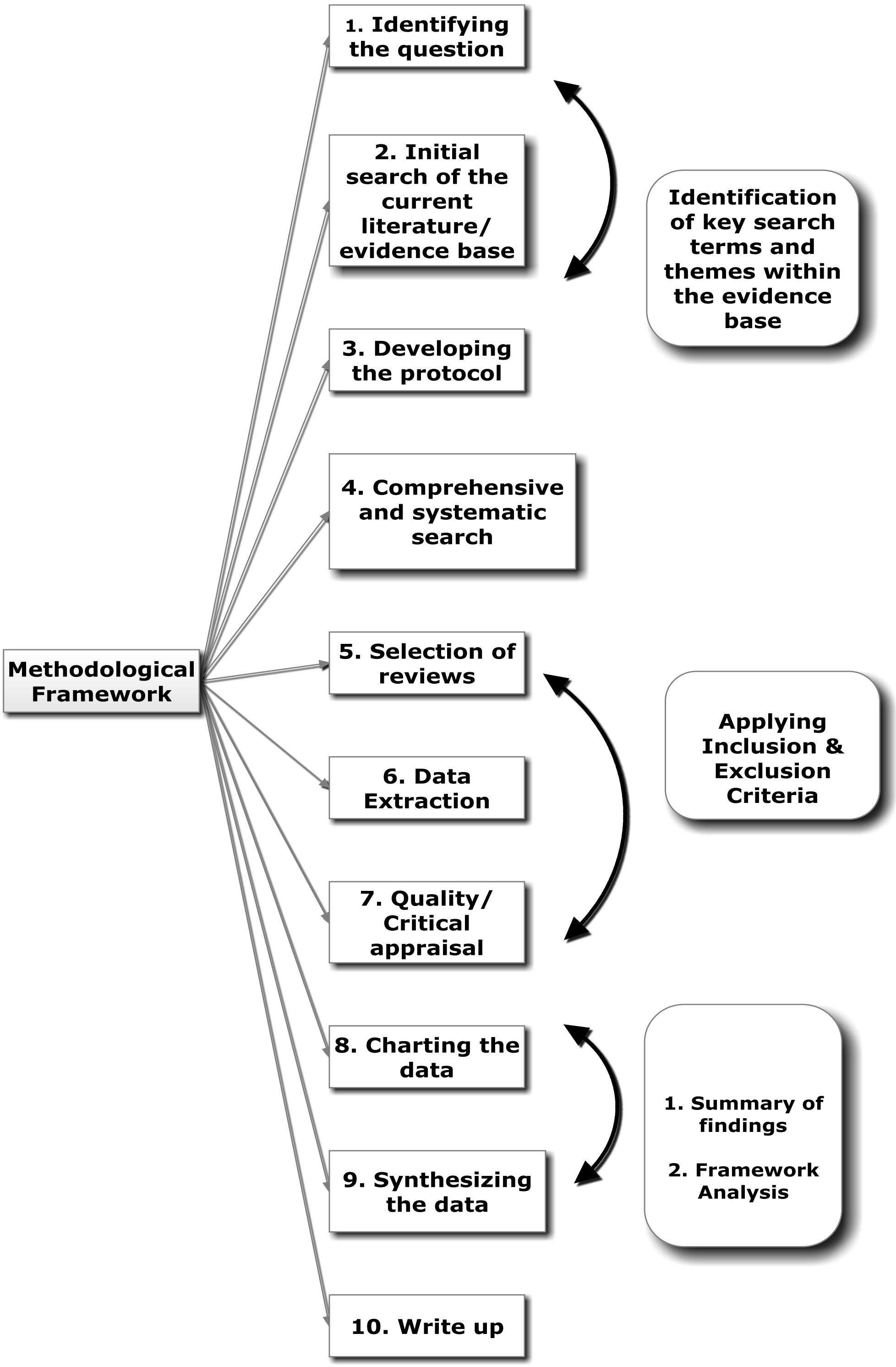
Harding et al (2011) suggest the primary goals of a review of research evidence is to enable practitioners to keep their knowledge up-to date, to help draft clinical practice guidelines and inform policy. However, it has become increasingly evident that healthcare professionals and policy makers need answers for complex questions about healthcare, which are not satisfactorily answered by traditional review methods, for example, narrative and systematic reviews (Forbes and Griffiths, 2002). In response, the methods for undertaking reviews to appraise, summarise and bring together existing research evidence in one report have rapidly evolved and developed.

Consequently, there are now a confusing plethora of different review designs (Gough et al, 2012; Norman and Griffiths, 2013). Indeed, Grant and Booth (2009) identified fourteen different types of reviews. Terms included: systematic review, literature review, meta-analysis, scoping review, umbrella review. Furthermore, there is still very little consensus on agreed methods to synthesise data, especially that from disparate study designs (Whitmore and Knafl, 2005; Harden & Thomas, 2009). What is apparent is how review methodologies are defined and applied depends on a number of important factors including amongst others: the philosophical and epistemological basis, and purpose of the review (Gough et al, 2012).

To add to the confusion and complexity when striving to obtain the best available evidence to inform clinical, policy and research decisions, the number of published reviews of varied value and scope has increased exponentially (Smith et al, 2011). Smith et al (2011, p.1) argue that methods for reviewing pre-existing reviews seem a logical step and are now required. Scopus and Medline were briefly searched and a number of such papers reporting reviews of reviews were identified, including: Berkof et al (2011), Hodges et al (2010), Ekeland et al, (2010), Francke et al, (2008), Swanson et al (1993). However, all used different review design strategies.

Little practical guidance on how to conduct a review of pre-existing reviews was found. Consequently, to help guide this review process, a relatively new review methodology that of scoping reviews was drawn upon (Brien et al, 2010). Defined by Armstrong et al. (2011, p. 147) as *a 'process of mapping the existing literature or evidence base'.* Scoping reviews provide a useful method to determine whether to proceed to a full systematic review of interventions (Brien et al, 2010). A systematic scoping review framework was developed by Arksey and O'Malley (2005), which includes the steps outlined in Figure 1, below. Quality appraisal is not usually considered necessary in scoping reviews (Armstrong et al, 2011; Grant and Booth, 2009). However, this review of reviews aimed to understand the nature and quality of research in this field. Therefore, a quality assessment of the reviews (using a tool developed by myself) was included.

Figure 1: Review Steps



2.3 Review Design

A review of pre-existing reviews following a systematic, stepped review process was conducted (guided by Armstrong et al, 2011; Arksey & O'Malley, 2005) as outlined in Figure 1, above. Framework analysis was used as a method to manage the data and aid synthesis of findings (Armstrong et al, 2011; Pope et al, 2007). The review process was iterative rather than linear, requiring reflexive engagement with each step of the process. Where necessary steps were redefined and/or repeated to ensure questions were relevant and feasible, and search strategies and processes were comprehensive and would meet the aims of the review. Reviews that systematically incorporated and synthesised the evidence from quantitative, qualitative or mixed-method studies were included if they met the inclusion criteria.

2.3.1 Inclusion Criteria

The criteria for inclusion of reviews were as follows:

Types of reviews:

- Papers addressing cancer carers' needs which are published in peer-reviewed journals.
- All review types and associated methodologies

Types of participants:

- Cancer carers over the age of 18, regardless of relationship to the patient, gender, the patient's disease type, or the treatment the patient has had or is having.
- Reviews of studies reporting data on both patients and carers (as long as data on carers has been reported and appraised separately).

Time-frame and language

- Reviews published between 1990 and January 2012[2].
- Reviews published in English language journals.

2.3.2 Exclusion Criteria

Reviews were excluded if they:

---

[2] Papers published prior to 1990 were excluded, as the trend for delivering chemotherapy treatments in the outpatient setting has only occurred in the last 15-20 years.

- Focused exclusively on the needs of and interventions for cancer patients.

- Focused exclusively on paediatric patients and their caregivers.

- Focused on carers under the age of 18.

- Focused exclusively on carers of palliative or end-of life patients.

- Did not distinguish between patients and carers when reporting data.

- Were published in a language other than English.

- Were published prior to 1990.

2.3.3 Search Strategy

Key terms found in papers yielded in the initial exploratory searches were used. A medical librarian provided independent input. This helped ensure the nomenclature was suitable and the search was sensitive enough to maximise capture of relevant reviews.

The following databases were systematically searched via the NHS interface HILO:

- MEDLINE (1990- current)
- CINAHL – Cumulative Index to Nursing and Allied Health Literature (1990- current)
- PsycINFO (1990-current)
- Cochrane Reviews - Database of Systematic Reviews
- DARE–Database of Abstracts of Reviews of Effects

To ensure that the search was as comprehensive as possible, the reference lists of reviews identified through database searching were examined and a hand search of the following journals was conducted:

- European Journal of Oncology Nursing
- Oncology Nursing Forum
- Cancer Nursing
- European Journal of Cancer Care
- Supportive Cancer Care
- Psycho-Oncology
- Journal of Advanced Nursing

2.3.4 Key Search Terms

To identify relevant reviews the search strategy combined four sets of key search terms, with all MeSH terms exploded to gain maximum capture:

Table 1: Search Terms

	AND	**AND**	**AND**	**AND**
Medical Subject Headings	**Participant 1**	**Disease**	**Intervention**	**Type of Study**
Medline ⟹	Caregivers **or** Nuclear Family **or** Family **or** Spouses **or** Sibling **or**	Neoplasm	Education **or** Counselling **or** Social Support	Review **or** Meta-analysis
PsycInfo ⟹	Caregiver burden **or** Family Members **or** Significant others **or** Spouses **or** Kinship **or** Family **or** Caregiver **or**	Neoplasm **or** Oncology	Intervention **or** Education **or** Social Support **or** Psychosocial factors	Systematic Review **or** Meta-analysis **or** Literature Review
CINAHL ⟹	Caregiver Burden **or** Caregivers **or** Caregiver Role Strain **or** Family	Neoplasm **or** Cancer patient	Education **or** Social Support **or** Psychosocial **or** Caregiver support	Systematic Review **or** Meta-analysis **or** Literature Review
Free-text searching ⟹ **applied across all databases**	Informal care* **or** Friend* **or** Relative* **or** Partner **or** Significant other* **or** Next of kin	Cancer **or** Oncology **or** Tumour	Supportive care **or** Intervention **or** Support* **or** Information* **or** Psychological **or** Psychosocial **or** Preparation* **or** Caregiver support	Meta-analysis **or** Realist synthesis **or** Research synthesis **or** Review

(* denotes plural or other truncation)

Limits placed on database searches were: only citations that focused on Adults, English Language and from Year 1990 to January 2012. The searches were run again from January 2012 to November 2013.

2.3.5 Data Extraction

Data from reviews was initially extracted and appraised using a standardised data extraction form developed with guidance from Pope et al (2007) and Petticrew and Roberts (2006). Data extraction parameters included: the review characteristics (e.g. authors, year of publication, country of origin and funding); purpose and process of review (aim, questions, review design, search and selection strategies); quality assessment (strategies the reviewers used to assess study quality); results (e.g. number of studies, presentation and synthesis of findings) a separate section was included for reviews of intervention studies (e.g. classification, contents, dose, outcomes); key discussion points (themes, theoretical concepts, critique of reviewed studies, limitations of the review, clinical application of findings, directions for future research and main conclusions). Finally two sections were included for comments on the whether the review theoretically informed this PhD study; and the overall methodological rigour of the review. The form which guided the data extraction process can be found in Appendix 1.

2.3.6 Quality Appraisal

Appraising the quality of the reviews was challenging. This was because there are no universally agreed frameworks or criteria for assessing the quality of evidence across all types and methods of primary studies or reviews (Mays, et al 2005). There are, however, a number of critical appraisal tools developed predominately for appraising the quality of integrative reviews evaluating treatment/intervention effectiveness, which incorporate a meta-analysis or narrative synthesis of findings (CASP, 2006; Liberati et al 2009; Shea et al 2007). Spencer et al (2003) developed a framework for appraising the quality in qualitative research and synthesis. Components of these assessment tools and questions they asked were incorporated into the data extraction form.

Fundamentally, there were two key questions, which guided the quality assessment of the reviews:

1. Is the review executed in a methodologically rigorous manner, evoking confidence in the reliability, validity and trustworthiness of the findings?

2. Have the reviewers assessed the quality of the identified studies?
    - If so how?
    - Is quality assessed utilising appropriate quality assessment criteria which are matched to the methodological design of the reviewed studies?

Over the last decade there has been much debate about how to assess the quality of reviews and whether literature reviews should ideally follow a systematic approach (Norman and Griffiths, 2013). Many argue that without a systematic and explicit approach, conclusions reviewers make could be unreliable and misleading. This is because a comprehensive search strategy and rigorous critique of the included studies has not been undertaken (Pluye et al, 2009; Pope et al, 2007; Pawson et al 2005; Forbes and Griffiths, 2002; Hawker et al, 2002).

For the purpose of quality appraisal, I have differentiated between reviews that have been conducted systematically and those that have not (Table 2, below). A scoring tool was developed, with questions based on the core elements of the definition offered by the National Information Centre on Health Services Research and Health Care Technology (NICHSR, 2011, below). Two further criteria were included. The first is founded on whether the conclusions the reviewers offer are consistent with the overall findings. The second assesses whether the review could be easily replicated. Reviews conducted systematically are defined as:

> *'a form of structured literature review that addresses a question that is formulated to be answered by analysis of evidence, and involves objective means of searching the literature, applying predetermined inclusion and exclusion criteria to this literature, critically appraising the relevant literature, and extraction and synthesis of data from evidence base to formulate findings'* ((NICHSR, 2011).

Table 2: How Systematic is the Reviewed Review?

Criteria for appraising how systematic the review process was based on the definition offered by the NICHSR (2011)	**Yes/No – (if unclear then mark as No).**	**Score** **Yes scores 1** **No scores 0**
1. There is a clear question		
2. The literature has been searched using objective PRISMA methods.		
3. Predetermined inclusion/exclusion criteria have been applied		
4. PRISMA methods for extracting the data have been used and are described		
5. Methods for synthesising the data have been used and are described		
6. The included studies/literature has been critically appraised		
7. The overall conclusions are consistent with all the evidence from the findings and synthesis?		
8. There is enough information for the review process to be replicated		
Total		**8 (is the total score that can be achieved)**

2.3.7 Management of Data for Analysis and Synthesis

Initially, a simplified thematic analysis approach as described by Aveyard (2010) was used. The first step in this approach is to summarise the data extracted from the reviews (Table 3). The second step entails re-reading the papers, identifying key themes and then applying codes to these themes. However, it became evident that this approach was too simple and unwieldy for the purpose of enabling data synthesis. Therefore, Ritchie and Spencer's (1994) framework for analysis was used, as it is considered a suitable method to systematically and explicitly display, analyse and combine the pertinent findings (Ritchie et al, 2003; Pope et al, 2007). The framework includes five steps:

1. **Familiarisation with the data**, by reading and re-reading the reviews

2. **Developing a thematic framework** derived from the review questions see Appendix 2 for the thematic framework. This essentially functioned as another method for data extraction.

3. **Indexing and coding of the data**, which involved reading and re-reading the reviews' findings and discussion section to extract the data. This data was then placed under different codes. This process is iterative, having completed the first extraction process the reviews were checked again to ensure all the relevant data had been extracted and recorded.

4. Once all the data from each of the individual reviews had been extracted, the next step is to **chart the data,** in a matrix format, excel spread sheets were used.

5. The fifth step involves **mapping and interpretation of the data**; patterns within the data were then explored and compared (Ritchie et al, 2003).

2.4 Results

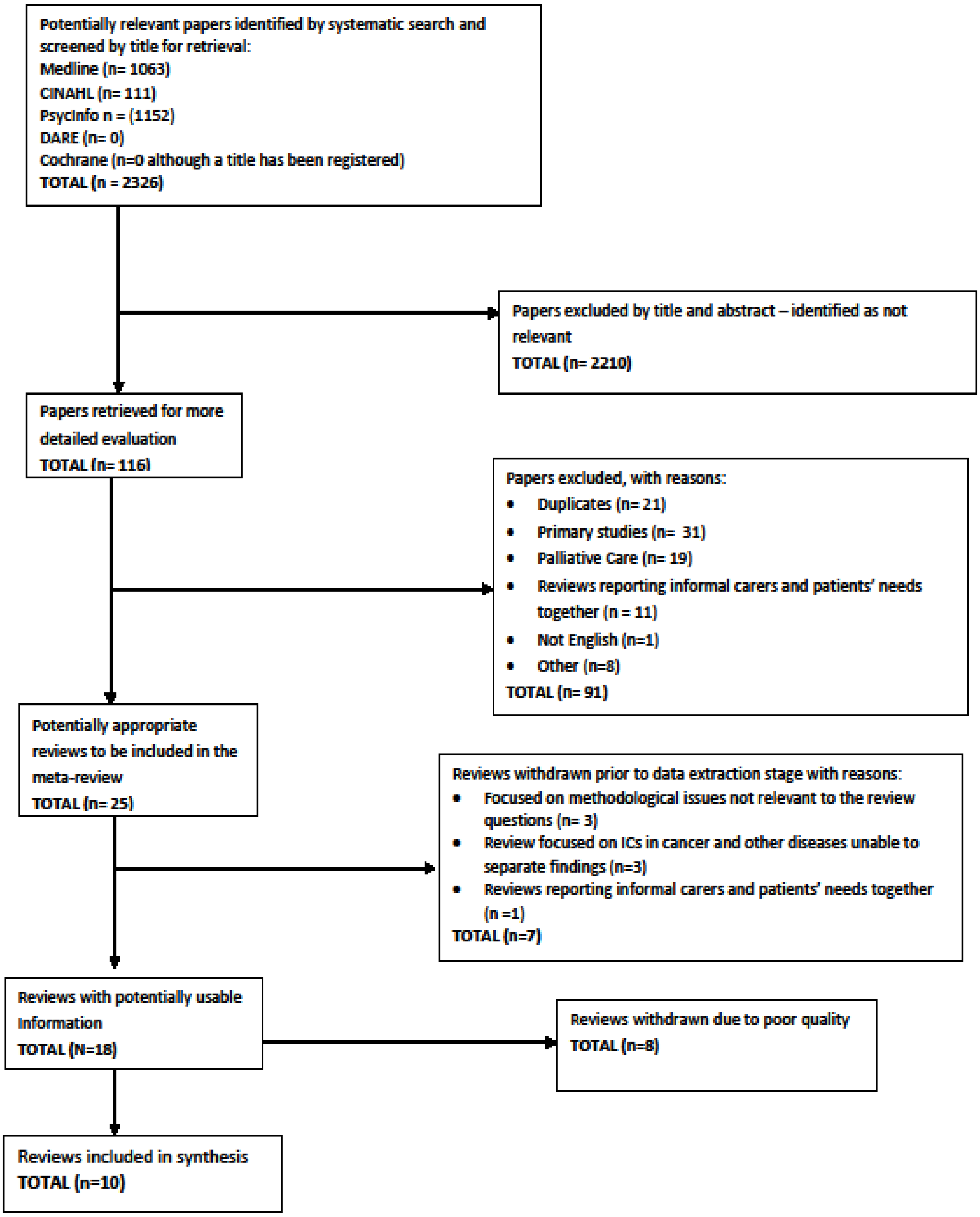
2.4.1 Review Selection

Overall ten reviews were selected for data synthesis in January 2012. Figure 2 below illustrates how these reviews were identified and selected from the search strategy. The searches initially identified twenty-five reviews as potentially suitable; however seven reviews were withdrawn before the data extraction stage (Burridge et al, 2007; Deeken et al, 2003; Harden, 2005; Mosher and Danoff-Burg, 2005; Nijboer et al, 1998; Schildman and Higginson, 2010; Swore Fletcher et al, 2008; Wen and Gustafoson, 2004). A further eight reviews were withdrawn once data had been extracted, as these reviews were appraised as poor quality, meeting none of the criteria outlined in Table 2 (Bevan and Pecchioni, 2008; Blum and Sherman, 2010; Glachen, 2004; Hardwick and Lawson, 1995; Kristjanson and Ashcroft, 1994; Laizner et al, 1993; Northouse, 2005; Pitceathly and Maguire, 2003). It would also have been difficult to extract data from these reviews as the findings had not been clearly presented or marked out.

When the original searches were conducted, a title had been registered with Cochrane Collaboration on psychosocial interventions for carers of people living with cancer. However, the protocol for this review had not been published. Since conducting this review, the protocol, but not the findings, had been published by Santin et al, in June 2012.

The search was updated in November 2013 following the previously used search strategy; this search garnered four more reviews, which met the inclusion criteria (Li et al 2013; Lambert et al 2012; Hopkinson et al, 2012; Regan et al, 2012). One further review by McCarthy (2011) was found through scanning reference lists of other papers. This review had previously been overlooked. Data was extracted from all these reviews. However, the data did not particularly provide any further insights. Furthermore, the findings of these reviews had not influenced how this study had proceeded. Therefore, the reviews were not incorporated into this chapter.

Figure 2: PRISMA Flowchart Illustrating Selection Process and Search



2.4.2 Summary of Reviews

Abbreviation Key: HPs = Healthcare professionals;

Table 3: Summary of Reviews

Author, Date, Profession & Country	**Type of Review as Defined by the Reviewers**	**Aim**	**Methods / Assessment of Quality**	**Findings**	**Gaps and Suggestions for Further Research**	**Limitations**	**Appraisal of Review Quality** **Score Out of 8**
Adams E. et al (2009) **Professional Background:** Psychology & Sociology UK	A literature review with Systematic Search: included all study designs published between 1998-2008	To examine the extent to which the information needs of partners and family members of cancer patients have been addressed in the literature	A systematic methodology was utilised The authors critiqued methodological strengths and weaknesses in the discussion section.	**32 papers** reviewed. Wide range of information needs: 11 main categories of need with a further 56 sub-categories were identified. Most of the research was undertaken in the diagnostic and treatment phase (n=23 studies) Treatment information related need: •Side effects (n=25 studies) •General treatment info (n=20 studies) •Nutrition (n=6) •Practical aspects of treatment (n=8) • Emotional Coping Information (n=22) e.g. dealing with patients and their own emotions Supportive care needs were more likely to remain unmet compared with medical needs.	More research is required to examine: • Carers in all disease types • Carers other than partners • How to meet the supportive care needs of carers Studies using larger sample sizes, validated tools, and longitudinal, mixed methods study designs	Several methodological limitations were highlighted including: poor reporting of theoretical underpinnings, & conceptualisation of ‘information need’. The studies were mostly cross-sectional in design and used invalidated tools Review’s limitations were not reported	**This review was scored as: 6**
Caress A.L. et al (2009)	Narrative Review All study	To describe and critique the research	Systematic approach	**19 studies** reviewed 1. Interventions with skills training (n =1) 2. Interventions to enhance care through	Well-defined theoretically underpinned and	Refusal rates reported in studies were high	**Score = 5**

Author, Date, Profession & Country	Type of Review as Defined by the Reviewers	Aim	Methods / Assessment of Quality	Findings	Gaps and Suggestions for Further Research	Limitations	Appraisal of Review Quality Score Out of 8
Nursing **UK**	designs	literature on interventions which may assist carers to provide physical care to family members with cancer	Quality assessment undertaken with guidance from the following: Crombie (1996); Guyatt et al (1993); CASP (2006)	managing symptoms (n=9) 3. Interventions with a problem solving focus (n=5) 4. Interventions with a learning focus (n=4) Carers appear to learn 'on the job' with little opportunity for well-planned learning opportunities – providing planned interventions acknowledged as complex	evaluated interventions are needed More research needed which focuses on practical care components and addresses specific points in the disease trajectory	The aim of the review was not achieved as well as the researchers would have wanted due to lack of detail provided about the interventions	
Couper J. et al (2006) Psychiatry **Australia & USA**	Review All study designs	To appraise published research on the psychosocial effects on women living with men diagnosed with prostate cancer (PC)	Systematic search methods used Quality of reviewed studies not explicitly assessed.	**44 studies:** reviewed Results were reported under 4 domains. 1. Psychological distress in partners (n= 7) found distress higher in partners than patients. 2. Coping patterns (n=8) 3. Impact on the couple relationship (n=4) 4. Psychosocial interventions (n= 3) Partners who use problem solving approaches, receive information or seek social support are less distressed and better equipped to help the patient.	All four domains required further research, particularly in the following: 1. To identify couples at risk of poor adjustment. 2. Devise feasible and effective methods/interventions to help partners of PC patients. Ethnicity rarely examined in this context.	The methodological problems of the studies reviewed were not consistently or rigorously critiqued. Review's limitations were not reported.	**Score = 2**
Honea et al (2008)	A systematic review of the	To evaluate and synthesise	Systematic review	**8** studies reviewed Key finding is the limited number of	The reviewers determined further	The quality of each individual study is not	**Score = 3**

Author, Date, Profession & Country	Type of Review as Defined by the Reviewers	Aim	Methods / Assessment of Quality	Findings	Gaps and Suggestions for Further Research	Limitations	Appraisal of Review Quality Score Out of 8
Nursing **USA**	literature. All study designs	the existing assessment tools and evidence regarding caregiver strain and burden	Studies appraised with CASP	interventions that are targeted toward carers. Interventions that were identified as likely to be effective included: **Psycho-educational:** structured programmes of information for carers **Supportive:** group and peer support **Psychotherapy and cognitive behavioural** Or multicomponent combinations of the above	research was required although not explicit in what this should be. Validated and sensitive measurement tools for caregiver burden need to be developed.	reported. While the review identified categories of potentially useful interventions limited detail is provided on the components of these interventions. Review's limitations were not reported.	
Kinnane N.A. and Milne D.J (2010) Nursing and Health research **Australia**	Review	To review the best available evidence for how carers use the Internet for cancer-related information and support. All types of studies included, including two reviews.	Systematic search, inclusion criteria, and CASP (2006) used to appraise studies. All retrieved studies were level IV evidence	20 studies were identified of these only **10 studies:** informed review based on quality of results Key findings were divided into three domains: 1. Information searching 2. Support group activity 3. E-mail use. Internet information and support should not replace the information support healthcare professionals provide nor be used instead of face-to-face communication but has strengths to use as a tool to enhance the service provision. Carers can become dissatisfied and there is a potential that care received from HPs is undermined if the carers perceives the internet provides more information than from HPs. Assessment of patients and carers internet use and ability is needed.	More research is required to examine Carers use of the internet and how it meets their needs. Interactive internet technology could be a potential intervention developed specifically for carers use and could have the potential to prepare, inform and support the carer How carers internet usage fluctuates over the disease trajectory e.g. more longitudinal studies	The studies reviewed were heterogeneous, with different aims, study tools, sample sizes and different cancer populations. Therefore, it is difficult to make generalisations. There was a 2-3 year gap between data collection and publication – internet and associated technology is rapidly expanding and developing. Review's limitations were not reported	**Score = 5**

Author, Date, Profession & Country	**Type of Review as Defined by the Reviewers**	**Aim**	**Methods / Assessment of Quality**	**Findings**	**Gaps and Suggestions for Further Research**	**Limitations**	**Appraisal of Review Quality** **Score Out of 8**
Kitrungrote L. and Cohen M.Z. (2006) Nursing **USA**	Systematic Review	To assess instruments of QoL used in family cancer caregivers of patient with cancer	Very brief methods section included: Databases searched. Key terms/words Brief inclusion criteria.	**28 studies: reviewed** 3 aspects of QoL were identified: 1.Descriptions of QoL of family caregivers 2. Positive/Negative Influences on QoL in Carers were categorised in 4 groups: patient or treatment related, the carer, the type of caregiving, and social factors. 3. No interventions found for improving the quality of life of carers in the acute phase.	Culturally sensitive tools that evaluate QoL are required. Longitudinal studies Future studies should clearly define concepts and theoretical underpinnings.	Limitations of the studies reviewed include: poor conceptualisation of QoL, lack of consistent definitions QoL, lack of theoretical frameworks. Review's limitations were not reported	**Score = 3**
Northouse L.L. et al (2010) Nursing **USA**	Meta-analysis of RCTs	To analyse the type and efficacy of interventions (RCTs) aimed at the needs of family caregivers of cancer patients.	Meta-analysis A theoretical framework was used to organise data, identification and selection, coding and statistical analysis. Publication bias assessed.	**29 studies** identified for meta-analysis only 9 of these focused solely on carers. **Characteristics and content of interventions**: 3 major types: Psychoeducational, skills training or therapeutic counselling. Most interventions were offered jointly to patients and carers. Variations in terms of dose, content and duration. Also variation in terms of disease stage but approx. 20% of the studies was early stage. The majority of carers were female, mean age 55 years, Caucasian (84%). Interventions were shown to have small to medium effects – improved QoL; increased coping, self-efficacy and reduced carers' burden.	The reviewers made numerous suggestions regarding future research: Research needs to address racial, cultural and socioeconomic diversity. Methods to identify high risk carers are required. Large, well-funded, multisite studies Effectiveness studies Evaluation of intervention costs	Difficult to delineate between interventions for carers in the Palliative Care and acute care phases. When, how and where the interventions were delivered was not identified in most of the studies and therefore not in the review e.g. stage of disease this made it difficult to tease out the findings. Low sample numbers and high attrition rates. 'Normal care' not identified.	**Score = 7**

Author, Date, Profession & Country	**Type of Review as Defined by the Reviewers**	**Aim**	**Methods / Assessment of Quality**	**Findings**	**Gaps and Suggestions for Further Research**	**Limitations**	**Appraisal of Review Quality Score Out of 8**
Resendes L.A. McCorkle R. (2006) Nursing **USA**	Integrative Review	To examine the literature on responses of spouses whose husbands have been diagnosed with prostate cancer and have undergone prostatectomy	Methodology section very brief included information regarding databases, brief inclusion criteria and keywords. Quality of the studies was not assessed	**Number of studies included not made explicit.** **1. Diagnosis and deciding treatment.** Spouses take an active, collaborative role in the decision making. Gathering information and peer-support used as coping strategies 2. **Post treatment period:** spouses reported feeling unprepared and often assume responsibility for managing side-effects. **3. The marital relationship:** experience brought couples together. **4. Information Needs:** spouses report discomfort in asking HPs for information. Substantial unmet need for information	Longitudinal studies RCTs of interventions that provide emotional and practical support Future intervention studies need to identify at-risk spouses who may have limited coping resources, poor mental health or a prior history of poor adjustment (however, they do not justify this statement).	How the papers were analysed is not reported. The studies were not systematically critiqued. Review's limitations were not reported. Evidence of researcher bias	**Score = 2**
Stenberg U. et al (2009) Nursing **NORWAY**	Systematic review: all study designs including reviews	To understand the complexity of the problems and responsibilities associated with cancer patients illness that family caregivers experience	Systematically undertaken No assessment of quality	**192 papers were included in this review** A total of 19466 adult family caregivers had participated in the reported studies. 63% were women, mean age 54 years old, most common cancers – breast and prostate. Over 200 problems and burdens were identified those most reported induced physical, social or emotional in combination. Carers' problems appear to be more psychological in acute treatment stage. Carers use descriptive words '*from spouse to nurse*'. Language carers use to describe roles important to consider when developing interventions	More research needed which explores the difference in symptoms, problems and perceptions in the caregiving experience from different socio-economic, cultural and racial backgrounds and how problems change during the illness trajectory.	The reviewers did not summarise the frequency of the problems nor did they assess the quality of the studies.	**Score = 6**

Author, Date, Profession & Country	Type of Review as Defined by the Reviewers	Aim	Methods / Assessment of Quality	Findings	Gaps and Suggestions for Further Research	Limitations	Appraisal of Review Quality Score Out of 8
Ussher J.M et al (2009) Psychology **Australia**	Systematic review	To systematically examine the efficacy of psycho-social interventions for reducing distress and improving coping in carers	A systematic qualitative analysis Studies were rated according to the NHMRC guidelines and Cochrane guidelines for RCT Not clear what strategy was used for synthesis	**25 studies included in review** – 13 of which were Level II RCTs NHMRC (1999) framework. 12 non RCTs. • Five of the 13 RCTs demonstrated little evidence of the efficacy of psycho-social interventions. • Eight of the studies showed significant effects, with moderate effect size. The 12 non-RCT studies did report positive results, across a range of domains. **Psycho-social interventions** not defined and intervention components were not made clear. Reviewers concluded that the evidence for specialised interventions for carers is not strong. Little evidence to make clinical recommendations to guide practice.	Research needed in: BME and different cultural backgrounds. Couple problems e.g. intimacy. Interventions targeted at different stages and tailored for individual need. For future research purpose of intervention and expected outcomes should be clearly based on theoretical frameworks and a prior needs assessment. Recruitment needs to be considered further as often there is 'gatekeeping' by HPs & patients	The limitations of this review were partly to do with how the reviewers chose to report the findings of the review and also because of the quality of the studies reviewed. It was difficult to delineate between disease stages. 'Normal care' not identified. Many methodological problems within studies identified: recruitment problems and small sample sizes. Nursing databases were not searched.	**Score = 2**

2.4.3 Review Characteristics

All included reviews (n=10) were published in the last seven years (Table 3 above). Half of these originated from the USA (n=5). Only three reviews identified the reviewed study origins, the majority of which were also conducted in the USA (Caress et al, 2009; Northouse et al, 2010; Stenberg et al, 2009).

The reviewers' professional backgrounds varied. However, they were predominately nurse researchers (n=7) while others came from backgrounds of psychology, sociology and psychiatry. It was deemed important to pay attention to the reviewers' backgrounds for a number of reasons. Professionals from different disciplines were likely to have different perspectives and reasons for working with carers; this then may have influenced which studies are incorporated into the review and how the findings are reported. Hawker et al (2002) also suggest that different groups will use different professional terminology and language, and this may influence which key words were used.

Diverse terms and definitions were used to describe carers and caregiving. This did not appear to be affected by professional backgrounds. However, only four of the ten reviews identified what a carer is and who the person who provided informal care to a cancer patient was (Honea et al, 2008; Kitrungrote and Cohen, 2006; Sternberg et al, 2009; Ussher et al, 2009). Sternberg et al (2009, p. 1013) defined the term carer as '*who the patient says it is'*, while Ussher et al (2009, p.85) identified carers as '*the family members and friends who provide both emotional and physical care for a person with cancer'*. Terms used to describe family members and/or caregivers were often used synonymously.

Most of the reviews included a disparate mix of studies with different research designs: qualitative, quantitative, mixed-methods and reviews. Only two papers Northouse et al (2010) and Ussher et al (2009) reviewed intervention studies evaluated by a randomised control trial (RCT).

All ten reviews focused on carers in the cancer setting. However, there was wide variability in the studies reviewed, in terms of the stage of cancer experience (newly diagnosed to palliative care) and point in the caregiving trajectory (specific point vs. any point). Most studies incorporated into the reviews did not report at which point in the disease process carers were supporting patients. Consequently, it was difficult to determine when carers' needs for support occurred, or when interventions for these needs were delivered. However, it was clear none of the reviews had reported on a study that had specifically examined the needs of and interventions for carers in the chemotherapy setting.

The aims and purpose of the selected reviews were also extremely diverse. Four could be broadly defined as reviews that explored the experiences and impact of caring for someone across the cancer trajectory; of these some included potential approaches for helping carers in clinical practice. Of these four, two reviews included studies investigating all types of cancer (Kitrungrote and Cohen, 2006; Stenberg et al, 2009) while the other two reviews focused solely on the experiences of prostate cancer patients' wives (Couper et al, 2006; Resendes and McCorkle, 2006). Of the other six reviews, one aimed to explore the information needs of partner and family caregivers in the cancer setting (Adams et al, 2009) and one examined empirical work focused on carers usage of the internet (Kinnane and Milne, 2010). The remaining four reviews concentrated exclusively on studies investigating interventions for supporting carers (Caress et al, 2009; Honea et al, 2008; Northouse et al, 2010; Ussher et al, 2009). Caress et al (2009) focused solely on interventions which aimed to support carers who provided physical care to patients with cancer. The other three reviews focused on all types of interventions.

Overall, it is not entirely clear how many studies in total were reviewed; as one paper did not explicitly state how many studies had been included in the review (Resendes and McCorkle, 2006). The other nine papers did identify the number of included studies included. The studies reviewed ranged from eight to 192. Lists of all identified and included primary studies were compiled and compared. Very few reviews had reviewed the same studies.

2.5 Quality Appraisal and Limitations of the Reviews

Two key questions guided the quality appraisal process. The first question focused on whether reviews were executed in a methodologically rigorous manner and evoked confidence in the trustworthiness of the findings. Of the ten included reviews, five achieved a score of five or above out of a total of eight. These reviewers had clearly conducted the review utilising a systematic approach. The processes for systematically searching the literature were also described in enough detail to be replicated by others. Of the ten reviews, the highest overall score achieved was seven out of eight; this review was the meta-analysis undertaken by Northouse et al, (2010).

There were a number of methodological weaknesses in all the reviews (Table 4).The reviews' questions and methods used for data extraction were not described in the majority of the papers. Synthesising the data from heterogeneous primary research, is perhaps the most challenging aspect of a review; with room for most errors to occur (Pope et al, 2007). Only two of the reviews clearly described the methods used to synthesise the findings.

The second question focused on whether the reviewers had appraised the quality of the selected studies. Six of the ten reviews had explicitly critiqued the included studies. The majority of these used the Critical Appraisal Skills Programme tools (CASP, 2006). Reviewers found numerous methodological limitations in the primary research studies. These included poor reporting of theoretical and conceptual frameworks, the studies were heterogeneous, with different purposes and aims, study tools were often not validated, small sample sizes, difficulties with low recruitment and high attrition rates and different cancer populations.

Table 4: How Systematic are the Reviews?

Review	**Question**	**Searches**	**Inclusion/ Exclusion Criteria**	**Data Extraction**	**Data Synthesis**	**Critical Appraisal**	**Conclusions**	**Process Reproducible**	**Total Score out of 8**
Adams et al (2009)	✓	✓	✓	✗	✓	✗	✓	✓	6
Caress et al (2009)	✗	✓	✓	✗	✗	✓	✓	✓	5
Couper et al (2006)	✗	✓	✓	✗	✗	✗	✗	✗	2
Hornea et al (2008)	✗	✓	✗	✗	✗	✓	✓	✗	3
Kinnane and Milne (2010)	✗	✓	✓	✗	✗	✓	✓	✓	5
Kitrungrote and Cohen (2006)	✗	✓	✓	✗	✗	✓	✗	✗	3
Northouse et al (2010)	✗	✓	✓	✓	✓	✓	✓	✓	7
Resendes and McCorkle (2006)	✗	✓	✓	✗	✗	✗	✗	✗	2
Stenberg et al (2009)	✓	✓	✓	✓	✗	✗	✓	✓	6
Ussher et al (2009)	✗	✗	✓	✗	✗	✓	✗	✗	2

2.5.1 Theoretical Underpinnings of the Research

Poor reporting of theoretical and conceptual frameworks was identified as a major limitation of the reviewed studies. Yet, the links between theoretical concepts and intervention attributes should be clearly outlined in intervention studies (Conn, 2007; MRC, 2008). Northouse et al (2010) found that some intervention studies incorporated in their review had used theory to identify hypotheses, guide the selection of intervention content and the choice of outcomes. However, most of the studies only made a brief reference to how theory was utilised in the study design or how it informed the interpretation of findings (Northouse et al, 2010; Adams et al, 2009). Northouse et al (2010) were the only reviewers to use a theoretical framework for organising their findings.

Five of the reviews identified a number of theoretical frameworks and concepts that had been used in some of the studies (Table 5). The Stress and Coping Model by Lazarus and Folkman (1984) featured more predominantly than others.

Table 5: Theoretical Frameworks

Review	**Theoretical Frameworks**
Adams et al (2009)	• Stress and coping theory (Lazarus and Folkman, 1984) • A supportive care framework (Fitch, 2000) • Family Systems Theory (Bowen, 1974)
Honea et al (2008)	Theory of caregiver burden and strain (Townsend, 1957; Yin et al, 2002)
Kinnane and Milne (2010)	Stress and coping (Lazarus and Folkman, 1984)
Northouse et al (2010)	Theoretical frameworks utilised by the reviewers • Stress and coping theory (Lazarus and Folkman 1984) • Cognitive behavioural theory (Bandura, 1997) • Quality of life frameworks (Cella et al, 1993; Ferrell et al, 1992) Types of theory identified by the reviewers: • Family care model • Cognitive behavioural model • Social support systems • Psycho-sexual counselling • Interpersonal counselling • Family COPE model • Labour of caregiving • Stress and coping (Lazarus and Folkman, 1984)
Ussher et al (2009)	• Systemic-transactional theory (Bodenmann, 2005) • The labour of caregiving (Brown and Stetz, 1999) • Patterns of carer coping (Wuest, 1997,2000,2001)

2.6 Findings: The Experiences, Roles and Needs of Carers

2.6.1 The Experiences of Carers

The findings generated through frameworks analysis (Appendix 2) clearly identified that providing informal care and support to cancer patients can significantly impact on a carer's life. Carers reported feeling overwhelmed by their caregiving role (Resendes and McCorkle, 2006). Carers not only struggled to manage the patients' emotional responses but also their own. Stenberg et al (2009) found that carers experienced different difficult emotional reactions, fear especially when the patient's condition changed, uncertainty, hopelessness, isolation and powerlessness.

Carers had numerous concerns relating to treatment side-effects, including: knowing what to monitor for, how to interpret the patient's symptoms and when to contact for advice or support from healthcare professionals to manage side-effects (Caress et al, 2009; Resendes and McCorkle, 2006). Carers reported feeling frustrated by the lack of information provided by healthcare professionals; usually only recognising they had unmet information needs when a crisis occurred (Stenberg et al, 2009). Not knowing what to expect or how to care for the patient caused great distress and anxiety for carers. Indeed Resendes and McCorkle (2006) found that partners consistently reported experiencing higher levels of distress than patients.

While many carers appeared to experience significant difficulties when caring for patients with cancer, a number of the reviews found there were positive reactions and rewards in caregiving. These included bringing the family or partners closer together and carers feeling good about themselves and their role (Northouse et al, 2010; Resendes and McCorkle, 2006; Stenberg et al, 2009, Ussher et al, 2009). However, these findings were greatly outweighed by negative reactions and undoubtedly were influenced by whether carers felt prepared and were confident.

How family and friends experienced caring for cancer patients was influenced by their gender, age and carers' perceptions of existing social support networks. Older carers themselves may have significant health problems, while younger adult carers may have more significant responsibilities, such as working and looking after young children or elderly parents (Resendes and McCorkle, 2006, Stenberg et al, 2009). Informal caregiving can also significantly impact on younger adult carers' abilities to work and their finances.

Women were more likely to be carers and affected by the responsibilities of caregiving (Resendes and McCorkle, 2006; Stenberg et al, 2009; Ussher et al, 2009). Ussher et al (2009) found that women were likely to report higher levels of depression and lower overall satisfaction with quality of life than male caregivers. However, female carers were more likely than male carers, to have better social support networks and would also seek peer support from other carers (Couper et al, 2006). Kinnane and Milne (2010) found that females were more likely to use internet support groups for obtaining emotional support, while male carers were more likely to seek factual information from these groups. Overall, being in receipt of support from social networks was found to be vital for carers of both genders to cope with their caregiving role. This support alleviates the distress caused by a diagnosis of cancer and improves overall quality of life (Couper et al, 2006; Kitrungrote and Cohen, 2006; Stenberg et al, 2009).

The nature of the relationship between the carer and the patient can impact on the caregiving role. Open and supportive communication between carers and patients significantly reduced distress in both. Avoiding talking to each other about the disease and its treatment had a negative impact on the carers' experience of caregiving (Northouse et al, 2010). Many cancer patients relied heavily on the carer for obtaining information and support. However, carers frequently hid their own concerns from patients in case it caused distress (Resendes and McCorkle, 2006; Couper et al, 2006; Kinnane and Milne, 2010; Ussher et al, 2009). Ussher et al (2009) found that carers were likely to regard their concerns as unimportant or irrelevant in comparison with those of the patient.

Caring for someone with cancer was found to significantly affect carers' health and well-being. Carers reported physical problems such as fatigue, trouble sleeping, lack of appetite and emotional exhaustion (Kitrungrote and Cohen, 2006; Stenberg et al, 2009). Northouse (2010) found that over half of those who provided care have chronic health conditions of their own, for example, heart disease and arthritis. These health problems were exacerbated by the 'stress of caregiving'.

Carers used a diverse range of coping strategies to help them support patients through cancer treatment (Couper et al, 2006). They actively searched for information as being informed was vital in helping them cope. Kinnane and Milne (2010) found the internet is increasingly used by many carers seeking information and social support via email and internet group activity. Kitrungrote and Cohen (2006) found that receiving social support and having contact with friends and families was an important coping strategy and significantly improved carers' quality of life.

The experience of carers receiving support from and communicating with healthcare professionals was reported on as frequently problematic. Carers had difficulties with receiving timely access to healthcare professionals and getting information from them (Kinnane and Milne 2010; Resendes and McCorkle, 2006). Coordination of the patients' care through the service was challenging and carers struggled to understand health care systems (Stenberg et al, 2009).

Caress et al (2009, p. 1525) found *'most carers are expected to learn on the job,'* with little input from healthcare professionals. Stenberg et al (2009) identified that carers used '*a different language'* and terminology to describe their caregiving activities than healthcare professionals would. This caused communication difficulties between the two.

2.6.2 Roles of Carers

Review findings indicated that carers have a number of important roles and often assume responsibility for complex tasks when supporting patients receiving treatment for cancer. Roles included that of '*information gatherer',* carers often became '*researchers*' checking up on healthcare professionals' treatment decisions (Couper et al, 2006; Kinnane and Milne, 2010; Stenberg et al, 2009). Carers were '*gatekeepers to information*' protecting patients from information that they believed may cause distress (Resendes and McCorkle, 2006). They acted as protectors and providers of emotional support and reassurance for patients. Carers were providers of practical support including: running errands, providing transport for hospital appointments and performing household tasks (Stenberg et al, 2009). However, family and friends who adopted these roles frequently did not recognise themselves as 'carers' especially if their main role was that of emotional support (Ussher et al, 2009). Kinnane and Milne (2010, p. 1133) report that carers,

> *'Play an important role in assisting the patient in adjusting to their diagnosis, to managing their cancer and in managing treatment-related side effects; by assuming these responsibilities, they enable cancer treatment centres to function'.*

However, while healthcare professionals expected carers to provide a vital health care resource (Kinnane and Milne, 2010), the caregiving role was often not recognised or supported by healthcare professionals (Resendes and McCorkle, 2006).

2.6.3 The Needs of Carers

Carers needed specific information and also practical and emotional help to undertake and cope with their caregiving roles while patients were receiving cancer treatment. Carers required information to help them understand the practical aspects of treatment, managing treatment schedules and medication administration (Adams et al, 2009). Carers used information to gain control over the negative aspects of the disease and treatment. A particularly important time for these informational needs to be met was when treatments began (Resendes and McCorkle, 2006). They needed tailored and specific information about how care was organised, who managed the patients' care, operational procedures, changes in care delivery, and when and who to contact when there were problems (Adams et al, 2009).

Carers' needs relating to the hands-on support they provided encompassed learning how to perform practical care skills. These included assistance with managing the medication and nutrition (Adams et al, 2009; Caress et al, 2009). Carers wanted to know how best to deal with the patient's emotions. They also needed help to cope with their own emotions, live with uncertainty and the stress caused by caring (Adams et al, 2009; Couper et al, 2006).

2.7 Findings: Helping Carers in the Chemotherapy Treatment Setting

2.7.1 Professional Roles

Only three reviews briefly mentioned the specific roles healthcare professionals undertake when supporting carers in practice (Honea, et al 2008; Kinnane and Milne, 2010; Resendes and McCorkle, 2006). The main role could be broadly defined as 'information providers', fulfilled by both doctors and nurses. Nurses were identified as being solely responsible for teaching practical skills to carers.

2.7.2 Potentially Useful Interventions

No studies were reported that specifically tested interventions targeted at carers who provided support for chemotherapy patients. However, the reviews reported supportive care interventions aimed at carers more generally in the cancer and palliative care settings. These were broadly categorised under three headings, psycho-educational, skills training and therapeutic/emotional support interventions (Northouse et al, 2010; Couper et al, 2006; Honea et al, 2008; Resendes and McCorkle, 2006). The majority of research-based interventions came under the heading of psycho-educational. The content of most of these addressed issues such as: providing information and teaching practical caregiving skills; maintaining relationships and self-care strategies (Northouse, et al, 2010). However, it is difficult to determine from these reviews what the interventions comprised, as components were not fully described.

There was considerable variation in the intensity and delivery of the interventions (Caress et al, 2009). Psycho-educational interventions were delivered in both an individual or group format (Honea et al, 2008). Northouse et al (2010) reported that 52 per cent of the interventions were delivered face-to-face to carers and/or patients by nurses, while 20 per cent were delivered by multi-professional teams. Kinnane and Milne (2010) identified some potentially useful interventions delivered via the internet or by email. These interventions could focus on providing up-to-date information that is easy to read and access. Peer support on the internet provides information and emotional support to carers; healthcare professionals could help carers by guiding them to useful internet sites (Kinnane and Milne, 2010).

Northouse et al (2010) reported a number of psycho-educational interventions were shown to have small to medium effects in the following outcomes: improved caregiver quality of life; increased coping, self-efficacy and reduced caregiver burden. Some of those aimed to improve psychological functioning were found to be unsuccessful in reducing depression in carers. The other three reviews investigating intervention efficacy found little evidence of benefit for carers participating in the included studies (Caress et al, 2009; Honea et al, 2008; Ussher et al, 2009). Indeed, Honea et al (2008) concluded, that no intervention identified in their review could be recommended for clinical practice. Caress et al (2009) reported that problem-solving interventions, which focus on improving carers' communication skills and managing medical tasks and side-effects showed promise. However, Ussher et al (2009) reported that, regardless of the mode of delivery, the reported qualitative findings revealed participants had high levels of satisfaction with the intervention.

2.7.3 Limitations of Intervention Studies

Many of the intervention studies reviewed were cross-sectional, qualitative, descriptive or non-experimental in design (Couper et al, 2006; Honea et al, 2008). Recruitment problems, selection bias and inadequate sample sizes were a particular problem in the intervention studies. Indeed Ussher et al (2009) recounted that those participating in interventions were often well adapted, highly functioning caregivers. They were not found to have elevated levels of stress or burden. Therefore, outcomes used to measure the benefit of participating showed very little effect. Ussher et al (2009) concluded that these participants were likely to be carers who wanted to participate for the purpose of '*gathering information*'. Ussher et al (2009) reported that there was evidence of patients and healthcare professionals '*gate-keeping*' preventing researchers from accessing carers in some of the reviewed studies.

Northouse et al (2010) and Ussher (2009) both reviewed randomised control trial (RCT) studies. However, most of these intervention RCTs were aimed at both patients and carers. Of the 23 RCTs that Northouse et al (2010) examined, only nine were aimed solely at carers and most of these were in the palliative care setting. Many of the reviewed intervention studies did not specify the stage of disease and were rarely targeted at meeting carers' needs at discrete phases (Northouse et al, 2010; Ussher et al, 2009).

One of the most important but unsatisfying findings is how researchers of research-based intervention studies have reported their methodology. Three of the reviews, which focused on intervention studies for carers, clearly identified that interventions were often poorly defined, with little explanation of their content or the actual components (Caress et al, 2009; Honea et al, 2008; Ussher et al, 2009). Furthermore, very little attention was given to who delivered or provided the intervention. These shortcomings then make it difficult for others to replicate the study. Northouse et al's (2010) meta-analysis found that some interventions investigated by RCTs had comprehensive protocols. However, these interventions were primarily focused on carers in the palliative care setting. These reviewers were the only ones who attempted where possible to contact researchers, requesting study protocols when information was lacking in the published reports.

2.7.4 Challenges and Barriers to Supporting Carers

Healthcare professionals' experiences and the challenges of supporting carers were rarely addressed in these reviews. Two reviews identified patient confidentiality and consent as a potential barrier to providing information to carers (Adams et al, 2009; Kinnane and Milne, 2010). While, Honea et al (2008) searched for clinical guidelines that could be used to help healthcare professionals support carers in the cancer clinical setting, none were found. Time or financial constraints, as a barrier to supporting carers, were only referred to in relation to healthcare professionals using email correspondence as a possible intervention for carers (Kinnane and Milne, 2010, p.1134).

It was reported that other challenges healthcare professionals may experience, when trying to support carers, came from the carers themselves. Ussher et al (2009) found that carers may not seek help or refuse support for two reasons. Carers viewed their own needs as irrelevant in comparison to the person they cared for, or they perceived themselves as coping and managing well. The language used by healthcare professionals to describe people, who care for cancer patients at home, for example, 'carers', may not be understood or recognised by the patient's caregiver; especially when it is predominately emotional support they are providing. They may find the term carer 'off putting' and are, therefore, less likely to engage with healthcare professionals (Stenberg et al, 2009; Ussher et al, 2009).

2.7.5 Enhancing Interventions

A number of the reviews identified how intervention studies could be enhanced. Strategies included purposively sampling for participants (carers) who were considered at risk of distress or not coping well with their caregiving role (Couper et al, 2006; Resendes and McCorkle, 2006; Ussher et al, 2009). Stenberg et al (2009) and Adams et al (2009) suggested that interventions for carers could be greatly improved if the language carers use to describe problems was understood and adopted by researchers and clinicians. Interventions should be aimed exclusively at carers, separately from patients, as interventions focusing on carers needs when delivered to both patients and carers, often resulted in less satisfactory outcomes. Carers' needs became secondary to the needs of patients (Northouse et al, 2010).

Interventions are needed that focus on specific points in the disease trajectory (Caress et al, 2009). Interventions could be greatly enhanced if they were tailored and targeted to the carers needs (Ussher et al, 2009). Very few of the reviewed intervention studies had a needs assessment as part of the intervention (Caress et al, 2009; Ussher et al, 2009). Finally, two reviews concluded that research and support in practice would be greatly enhanced if researchers and clinicians (from different professional backgrounds) worked together to identify and implement evidence based interventions for supporting carers (Couper et al, 2006; Northouse et al, 2010).

2.8 Discussion

No studies were identified that had specifically explored carers' needs and interventions for these in the chemotherapy setting. Most of the primary studies focused on carers generally across the disease trajectory or during the terminal phase of the disease. However, Colbourne (2008) suggests that it is problematic for researchers to try to separate the impact and experience of undergoing chemotherapy from the experience of receiving a diagnosis, investigations, other treatments and follow-up care. These processes often overlap and are considered to be in the same phase of the disease trajectory (Colbourne, 2008). As highlighted in Chapter 1, chemotherapy treatments do not occur in isolation nor occur as a once only episode and may continue for months or even years (Simcock, 2013). This may explain why there has been a lack of research that has focused specifically on this area.

It is clear from the findings of this review that cancer and its treatment has a significant physical, emotional and social (predominately negative) effect, on the lives of those that support patients who have cancer. Similar to the studies reported in Chapter 1, the findings revealed that patients rely on and look to family and friends to informally provide care and support while they are having treatment (McIlfatrick et al, 2006a; Thomas et al, 2001; Ream et al, 2010, 2013). Carers assumed a number of important roles, including that of '*information gatherer*', '*protector*' and '*symptom monitor*' when supporting patients having cancer treatments.

The findings revealed that carers of cancer patients receive little preparation, information, or support from healthcare professionals to help them perform their caregiving roles. Yet carers had specific treatment related needs, including: information about probable side-effects and how to monitor for them, how to interpret the patient's condition, and when they should contact healthcare professionals for advice and support. They also had significant emotional needs relating to managing the patient's emotions and also their own. If these needs are left unmet, carers' physical and emotional well-being can be seriously affected. Arguably this will impact detrimentally on the support and care patients' receive.

Support carers receive from social networks can significantly impact on their experience of caregiving. Couper et al (2006) found that couples who had less social support were more likely to experience elevated levels of distress, compared to those who had good social support. The findings from these reviews highlight that many carers rely on their networks for informational, instrumental and emotional support. Firth (2006) suggests that many family carers do not want or need help from healthcare professionals; as they are able to draw upon their own resources to manage the caregiving situation.

The findings exposed that assessment of carers' needs is missing from clinical practice and as a component of many research-based interventions. This was a surprising finding. Effective supportive care interventions must be established upon or coordinated with carers' needs within the context of their unique circumstances (Fitch 2000; NICE, 2004). Undertaking a formal assessment of carers' needs at the point of initiating chemotherapy treatment and then throughout the treatment phase could also be viewed as an intervention in itself. It would legitimatize carers' roles; offer an opportunity for carers to discuss their concerns and highlight areas that require intervention. Furthermore, it would provide carers with a clear indication that the patients' healthcare professionals welcomed carers and were interested in their concerns.

Carers reported problems in relation to communicating with healthcare professionals. While carers view the health professional as a key source of information, carers could be considered as a vital resource for healthcare professionals, as they often possess essential information about the patient. Strategies that enhance communication between the two would greatly enhance the support and care the patient receives. Psycho-educational interventions, which focused on enhancing carers' communication skills showed promise (Caress et al, 2009). However, there was little description on how this was achieved.

The findings revealed there is limited evidence to provide guidance on how healthcare professionals could help carers in the chemotherapy setting. What evidence there is for professionally-led supportive interventions for carers is a confusing mix of benefit, ambiguity and deficit. This might be because of how research-based interventions were reported in the primary study but arguably it is also due to the complexity and variability of the interventions and methodological challenges of assessing intervention efficacy. Very few of the reviewers had described conducting research to develop feasible interventions for carers as a complex undertaking. Yet, supportive, psychosocial interventions such as the ones examined in these reviews are characteristically complex (Redfern et al, 2008; Forbes, 2009; MRC, 2008). They are often multi-faceted, aimed at multiple outcomes and are usually problematic to implement or measure (Redfern et al 2008).

Very few of the intervention studies had conceptualised key constructs, such as who the carer was, who should professionally support them, what the current care provision is or what needs to be changed. When developing complex interventions such as these, the problem, how it will be addressed and who it is aimed at, needs to be conceptualised utilising established theory (MRC, 2008; Forbes 2009).

All the reviews identified that many of the research-tested interventions were not well defined. Intervention studies provided little information of the content or actual components. Forbes (2009) suggests that this is a common problem in nursing intervention research and has been described by De Jong et al (2004) and Conn (2007) as the 'black box'; whereby published reports of intervention studies rarely provide enough detail to inform the reader about the composition of the intervention, who the providers were and how it was delivered. All intervention studies should, therefore, provide information about the content of the intervention, its proposed mechanism, method of delivery and targeted outcomes (Mohler et al, 2012).

The reviews highlighted few challenges or barriers that healthcare professionals face in the provision of effective supportive care to carers. Yet they must have them. Hudson et al (2004) found that healthcare professionals encounter numerous barriers, preventing them from providing effective support to carers during the palliative phase of the disease. These included: those imposed by carers themselves, and those resulting from a lack of organisational and professional resources such as time, competencies, skills and guidance. It is not inconceivable that healthcare professionals working in the acute sector will have similar and different challenges. Developed supportive care interventions must not only meet the needs of carers, service providers must also be able to deliver them effectively. Healthcare professionals work within complex organisations and services, which currently have financial and resource constraints imposed upon them. If developed interventions are to be feasible, then understanding the complex nature of supporting carers in the chemotherapy treatment setting from the healthcare professionals' perspective is imperative.

2.8.1 Implications for Study

A major task of this review of reviews was to determine whether a systematic review of interventions for carers in the treatment phase would be viable and worthwhile to do, as recommended by the MRC (2008). The findings revealed that conducting a meta-analysis of research-based interventions would be of little benefit. It would be difficult to establish, from previously published reports, a theoretical understanding of the rationale for developing the intervention, or what the intervention would aim to change and how that could be achieved.

There were a number of issues that did need further consideration. These were as follows:

- To further substantiate the specific needs for information, practical and emotional support of carers in the chemotherapy treatment setting.
- To explore healthcare professionals' experiences of and needs for supporting carers.
- To observe interactions between carers, patients and healthcare professionals.
  - Listen to and explore the terminology and language used to describe roles.
  - Observe how people in this setting communicate with each other.
- To engage with other professionals from different disciplines.
- To explore how best to develop interventions for complex social problems.
- To avoid creating the 'black box' of research-based intervention studies, by clearly defining the purpose and components of the intervention.

2.8.2 Limitations of this Review of Reviews

This review of reviews has a number of important limitations. Firstly the search strategy was restricted to the English Language; however, very few non-English publications were identified in the initial scoping search or subsequent searches.

Another obvious limitation is that this review was conducted by an individual researcher. Ideally systematic reviews should be undertaken by a team of researchers, each bringing individual expertise and perspectives to the research process (Arksey and O'Malley, 2005). More than one reviewer can also bring greater reliability to the findings of the review and can avoid 'data extraction bias', whereby an individual reviewer might only extract data that fits with their views (Petticrew and Roberts, 2006).

The findings of this review are based on reviews of primary studies, rather than on original primary research reports. Thus, reliability and validity of this review's findings could be undermined in a number of ways. Firstly, similarities can be drawn between reviewing reviews and the party game 'Chinese Whispers'. This game involves one person whispering a story to another, until the story has been passed on to all those present. This retelling of the story often results in the final version being very different to that of the original. Likewise findings from the original research study can become diluted and distorted within a review; a review of pre-existing reviews could further compound this distortion. This could result in the overall findings of the review being far removed from those in the original studies. Furthermore, reviews can only provide a summary of the findings of primary research and can lack specific details. Gaining an in-depth understanding obtained by examining primary studies could potentially be lost (Hodges et al, 2010).

The only way to overcome these limitations would be to appraise all the original studies in the review, defeating the purpose of reviewing reviews. However, a sample of studies was selected from each review. An examination of these papers revealed that reviewers had, on the whole, accurately reported the findings from the original study. It also confirmed that few primary intervention research reports had comprehensively described components of the tested interventions.

The findings of any reviews of primary research may not include the most up-to date evidence or published reports. However, to avoid missing recent and pertinent publications new publications relating to carers and healthcare professionals in this setting were searched for throughout the duration of the study. Any reports of primary research or reviews, which were found to be relevant, will be highlighted in the discussion chapter of this thesis (Chapter 8).

The quality of the reported findings relies on the quality of the included reviews, and the quality of these relies on the quality of the primary studies that were included in the review. As previously identified, many of the reviews and primary studies had methodological weaknesses and limitations. The quality appraisal undertaken scored reviews out of eight, the quality scores ranged from two-seven, (median = 4.1). The findings of this review, therefore, must also be treated with caution. However, the key objective of this review was to examine the extent, range, quality and nature of research activity in the field of carers in the treatment cancer setting, reviewing pre-existing reviews enabled this.

2.9 Chapter Summary

This review of reviews has identified a number of areas where there were significant gaps in both research and clinical practice. The findings demonstrated that while carers adopt vital caregiving roles, these roles remain unrecognised and unacknowledged by practitioners. What is not certain is why this occurs. While the findings provided some insight into the needs of cancer carers, their specific needs during chemotherapy were less distinct. No interventions were found, which specifically focused on supporting carers in the chemotherapy treatment setting. However, research-based interventions, which aimed to meet carers’ needs more generally across the disease trajectory, have failed to be implemented in practice. It is not entirely clear why this is the case. However, one of the most illuminating findings is the experiences and needs of healthcare professionals in this aspect of care, have been a neglected area in practice and research. If research-based interventions are to be feasible and acceptable, an understanding of the complex nature of supporting carers from practitioners’ perspectives is essential.

These gaps required further exploration for the purpose of meeting the aim and objectives of this study. This study’s overarching research question was: How can healthcare professionals intervene to prepare and support carers of chemotherapy patients? Yet, the findings of this review rather than provide answers and solutions, revealed further questions, which needed to be addressed. These include:

1. What are carers' specific needs for supporting patients through chemotherapy?
2. How are carers' needs currently met in the chemotherapy treatment setting?
3. If carers' needs are not addressed, why is this?
4. What are the experiences and needs of healthcare professionals when supporting carers?
5. How should supportive care interventions be developed?

Chapter 3 Methodology: Developing Complex Interventions

> *"Never doubt that a small group of thoughtful, committed, people can change the world. Indeed, it is the only thing that ever has."* (Margaret Mead)

3.1 Introduction

In the previous chapters the complex nature of cancer care and informal caregiving has been highlighted. Throughout this chapter the numerous aspects of complexity involved when developing interventions will be addressed. Different perspectives including those from social sciences, organisational change management and implementation theory have been drawn upon. This chapter tells the methodological story of this study, how the concepts evolved, while also describing and justifying the approach taken to meet the aims of the study.

3.2 Why the MRC (2000, 2008) Framework?

An important finding, from the review of reviews was that interventions for carers who supported cancer patients across the disease trajectory had failed to be implemented in practice. What was not clear was why this occurred. The MRC (2000, 2008) framework for developing and evaluating complex interventions was, therefore, initially used for pragmatic methodological reasons. It essentially provided a launching point for understanding how interventions could and should be developed. One of the key strengths of this framework is that it allows flexibility in the choice of study design. Using the framework enabled the methodology to evolve as the study proceeded. It is recognised that developing interventions to address complex social problems, such as the one being addressed in this study, is challenging (MRC, 2008). The framework provided guidance, helping to unravel what would make an intervention complex and what was complicated about developing interventions.

3.3 What are Complex Interventions?

The MRC (2000) and Campbell et al (2000) describe complex interventions as actions that change or improve the quality of individual patient care, service delivery and/or health provider behaviours. Other types of complex healthcare interventions are those focused at promoting health or changing health behaviours, smoking and diet, within a community or population. Another description is offered by Redfern et al (2006, p. 2411) who followed the MRC (2000) framework, to develop a complex intervention for improving risk factor management after a stroke. They described complex interventions as *'educational or psychosocial interventions aimed at changing knowledge, beliefs or behaviours'*.

The MRC state that interventions which aim to change behaviour or practice are complex when they have *'several interacting components that may act independently and inter-dependently'*

(MRC, 2008, p. 7). It is recognised few healthcare interventions are simple; most are multifaceted (Forbes, 2009; Craig et al, 2008). It is, therefore, difficult when evaluating the effectiveness of an intervention to ascertain, which component or combination of components had the desired effect and resulted in change. The MRC (2008) states there are various dimensions of complexity that should be considered when developing interventions:

- *Number of and interactions between components of the interventions*
- *The number and difficulty of behaviours required by those delivering or receiving the intervention*
- *The number of groups or organisational levels targeted by the intervention.*
- *The number and variability of outcomes*
- *The degree of flexibility or tailoring of the intervention that is permitted*.

MRC (2008, p. 7)

3.4 Alternative Views of Complexity

The MRC (2008) provides some explanation for the complexity involved when developing healthcare interventions. However, theories of complexity highlight that healthcare interventions are delivered within complex adaptive systems (Wheelan, 1996; Shiell et al, 2008; McDaniel et al, 2009). These systems are defined by Plsek and Greenhalgh (2001, p. 625) as, *'a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions change the context for other agents'.* Agents within clinical settings include patients, relatives, clinicians, administrative staff and others working within or aligned to the organisation, for example, primary care. Since all these agents are interconnected, introducing a small change in one area can create a much greater impact somewhere else in the system (Shiell et al, 2008). In these systems it is frequently difficult to determine the causal factors of change or account for what, Shiell et al, (2008) describe as 'spin-off' effects. Additionally, due to the unpredictable nature of agents, new interventions aimed at changing practice in one part of the system can be prevented or used differently by agents from another.

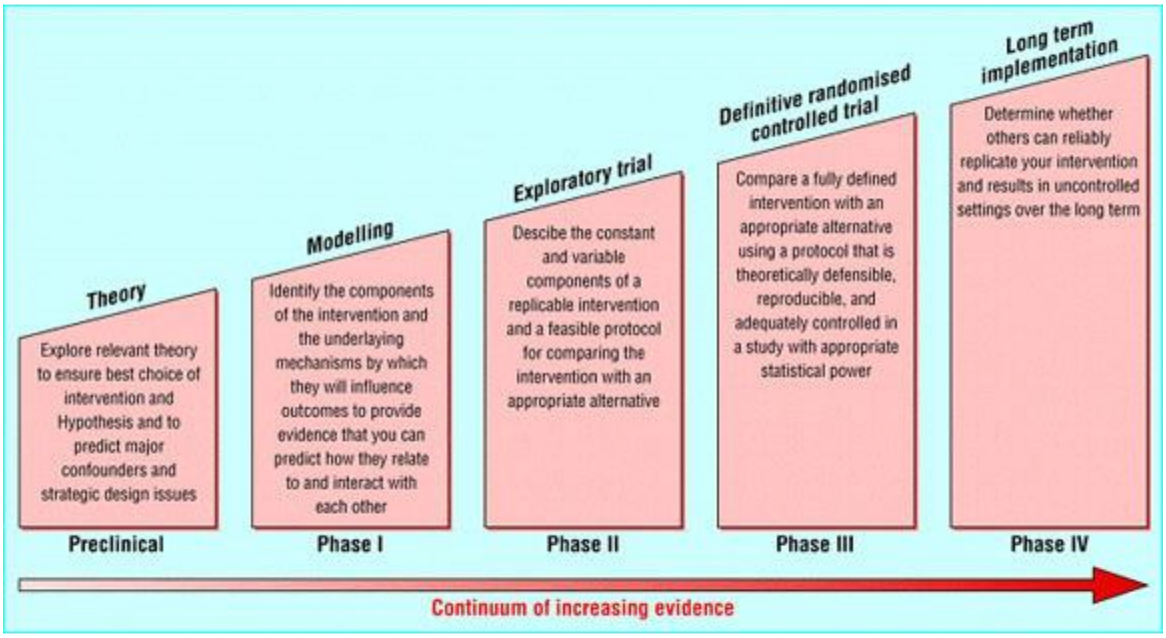
Agents or healthcare professionals working within these systems have different professional backgrounds, priorities and goals. Nurses and doctors, for example, may share an overarching professional aim to provide good patient care, but their attitudes and perceptions of good patient care and how they work towards providing it may be in conflict (Holloway and Todres, 2010). Therefore, while one group may see the need for change others may not. Another example of complexity in clinical practice is that while patients may present with similar problems, the context and presentation of these problems will alter every time. This requires interventions to be flexible and tailored to the needs of the individual, while also considering the needs of the system. Thus, an intervention may be simple but when introduced into a complex adaptive system it is the system rather than the intervention that creates the complexity (Greenhalgh et al. 2004).Understanding the organisation of the service and how agents and systems are interconnected and interact is essential when developing interventions (May et al, 2007; Murray et al, 2010; Plesk and Greenhalgh, 2001).

3.5 Background to the MRC Framework

The original framework developed by the MRC was initially published in the British Medical Journal, in what has now become a highly influential paper (Campbell, et al, 2000). The framework was proposed in response to an increasing awareness that developing and evaluating complex healthcare interventions is extremely difficult and involves understanding and managing change processes. Additionally, many interventions developed through research had failed to be successfully translated into practice. For those funding healthcare research this had serious economic implications with millions of pounds being spent on clinical trials which seemingly failed to produce results. What was often unclear is whether interventions had failed to be translated due to ineffectual implementation strategies or because the intervention was not fit for purpose and hence unsuccessful (Craig, et al 2008).

The aim of the original framework was to help researchers apply a planned, sequentially phased approach, predominately for development of complex interventions evaluated by randomised controlled trials (RCTs), see Figure 3 below (MRC, 2000, p.3; Campbell et al, 2000). It was thought that following a systematic approach would improve the developmental process and probability of interventions being adopted by practice. The design of this framework was based on models used for developing new drug treatments (Craig, 2008). The original framework, although considered extremely useful, had a number of limitations (MRC, 2008, Campbell, 2007). It was found in reality that linear approaches for developing interventions, aimed to address complex social problems, rarely work.

Figure 3: The Original MRC (2000) Framework



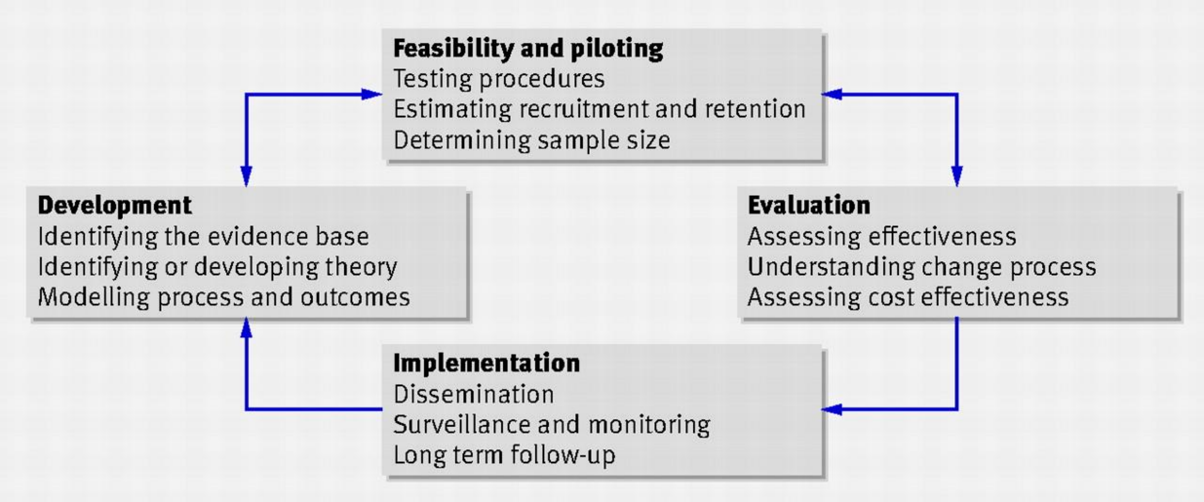
The MRC revised and released the updated framework in 2008. Evaluation of interventions through RCTs is considered best practice (Blackwood, 2006). However, evaluating complex interventions through RCTs is challenging. It is often difficult to randomise participants and to identify the ‘active ingredients’ and, consequently, standardise the intervention so that it is replicable and reproducible in different sites (Blackwood et al, 2010). Therefore, in this new version it was acknowledged that other types of experimental and non-experimental designs, not just RCTs, may be appropriate for evaluation purposes (Craig et al, 2008). It was recognised that a more flexible and iterative process was needed, less closely aligned to the phases of pharmaceutical development. The first two phases and the last implementation phase had been identified as the most challenging to do well. More guidance was provided on how to approach these phases, including recommendations to use qualitative research methodologies where appropriate (Campbell et al, 2007). Researchers were also advised to take into account the local context in which the intervention would be delivered and recognise the social, political and economic factors that may impact on the development and evaluation of the intervention.

Another framework for the development and evaluation of complex interventions has been designed and published by a team of nurse academics in the Netherlands (van Meijel et al, 2004). This framework consists of four phases, the first is described as the problem definition stage, the second the accumulation of building blocks for intervention design, third the intervention design and finally intervention validation. Both frameworks have overlapping constructs and highlight the importance of using theory to develop the intervention and comprehensively pilot test (Sturt et al 2006; Blackwood, 2006; Mohler et al, 2012). Both also state the problem, the intervention aims to address, must be clearly defined.

3.6 The Phases

As can be seen in Figure 3 above, the original MRC (2000) framework consisted of five sequential phases, the pre-clinical phase (or phase 0), the modelling phase (phase 1), the exploratory pilot phase (phase II), the definitive trial (phase III) and the implementation phase (phase IV). While, the updated guidance recommends considering phases 0, 1 and 2 of the original framework as part of *'one larger iterative activity'* (MRC, 2008, p. 8) as depicted in Figure 4 below, all five phases should still be completed when developing interventions. The MRC (2008) warns that appropriately working through these five phases can be a time-consuming process. However, not completing or omitting phases will result in *'weaker interventions that are harder to evaluate, less likely to be implemented and less likely to be worth implementing'* (MRC 2008, p. 4).

Figure 4: Development of Complex Interventions (MRC, 2008)



The MRC framework while providing a useful guide for developing interventions does not prescribe the methods that should be used within each of the phases (Redfern et al, 2008). As previously suggested, this allows researchers flexibility in the research design. However, initially, this lack of in-depth guidance was confusing. Databases were explored to find published studies that had used the MRC framework. A significant amount of published studies underpinned by the MRC framework since it had been originally published were found (for example, Blackwood, 2006; Bradley et al, 2010; Bradshaw et al, 2010, 2012; Burgess et al, 2008; 2012; Farquhar et al, 2010; Redfern et al, 2006, 2007, 2008; Murchie et al, 2007; Sturt et al, 2006). There was a scarcity of intervention implementation studies. However, it was apparent researchers had employed a diverse range of methods for designing their interventions, while following the MRC framework. Indeed not one study was found that had used the same approach as another. The approaches ranged from the simple to very complex methodological designs.

A team from King's College London developed a psycho-educational intervention to promote early presentation of breast cancer, which has been translated successfully into clinical practice. The team used the MRC framework to guide latter phases of the study, having started the work in 1998 with a systematic review (Burgess et al, 1998; 2008; 2009; 2012; Forbes et al 2011; Ramirez et al, 1999). Developing feasible interventions takes considerable time, especially when the full extent of the problem you wish to address is not fully understood (MRC, 2008). Van de Ven (2007) suggests very often researchers seek and implement solutions rather than taking the time to conduct an in-depth analysis of the problem and its causes. This doctorate study, therefore, focused on the developmental stage of the intervention, the pre-clinical and modelling phases of the framework.

Ideally the development process should begin with a systematic review to determine the scope and nature of the problem and identify what is already known about previously developed interventions. However, it is recognised, as found in the review of reviews, that frequently there is little published research evidence to help provide a clear description of the problem and how an intervention is likely to address it and how theoretically an intervention would work (Campbell et al, 2007). The MRC (2008) recommends when this occurs new primary research should be conducted. However, the methods employed will depend on the research question (Craig et al, 2008).

The modelling phase is concerned with defining further the intervention's components and how they interrelate (Blackwood, 2006). While also determining its potential effects, through experimenting by hypothesising about and testing for, how the intervention may cause the desired change (Michie et al, 2008, 2011; Burgess, et al, 2009). There appears to be many different approaches, which can be used for this phase, including computer simulations or economic evaluations (MRC, 2000). Qualitative methods, such as focus groups or small observational studies are also useful for modelling the intervention (MRC, 2000). Hypothesising and re-testing components of the intervention may need to occur numerous times, until a thorough understanding of the intervention and the determinants of change are realised. It is at this point the intervention can be tested in an exploratory pilot study, before a larger evaluation study, such as a RCT is conducted (MRC, 2000).

3.7 Theories of Behaviour and Organisational Change

It is acknowledged that changing behaviours can be an extremely difficult and complex process (Grol, et al, 2013; Hayes, 2010). Therefore, behaviour and organisational change theories should be drawn upon when developing interventions; to gain an understanding of what needs to be changed, identify appropriate strategies for changing behaviour and for measuring and evaluating the effectiveness of the strategies used (Craig et al, 2008; Michie et al, 2009). Cane et al (2012, p.37) state that *'designing interventions on the basis of practitioner or researcher intuition rather than theory precludes the possibility of understanding the behaviour change processes that underlie effective interventions and of applying this knowledge to inform the design of future interventions'.* Poses (1999) proposes pursuing this understanding frequently adds further complexity to the design process. However, the final product is potentially an intervention, which is simple, relevant and effective.

Although recognising, from the onset of this study that developing an intervention to support carers in the chemotherapy setting would require a change of behaviours (Campbell et al 2007), it was unclear, on whose and/or what behaviour would be the target for change. However, there were four interrelated groups, whose behaviours, attitudes and knowledge needed to be fully explored and understood, before an intervention could be designed. These groups included healthcare professionals, the organisation, patients and carers. In Figure 5 below, I also included myself, conscious that the researcher's professional background, personal values, knowledge and beliefs would influence the development of the intervention. As suggested by the MRC (2008) external factors would also need to be considered, such as the current political landscape and societal expectations of supporting carers in clinical practice.

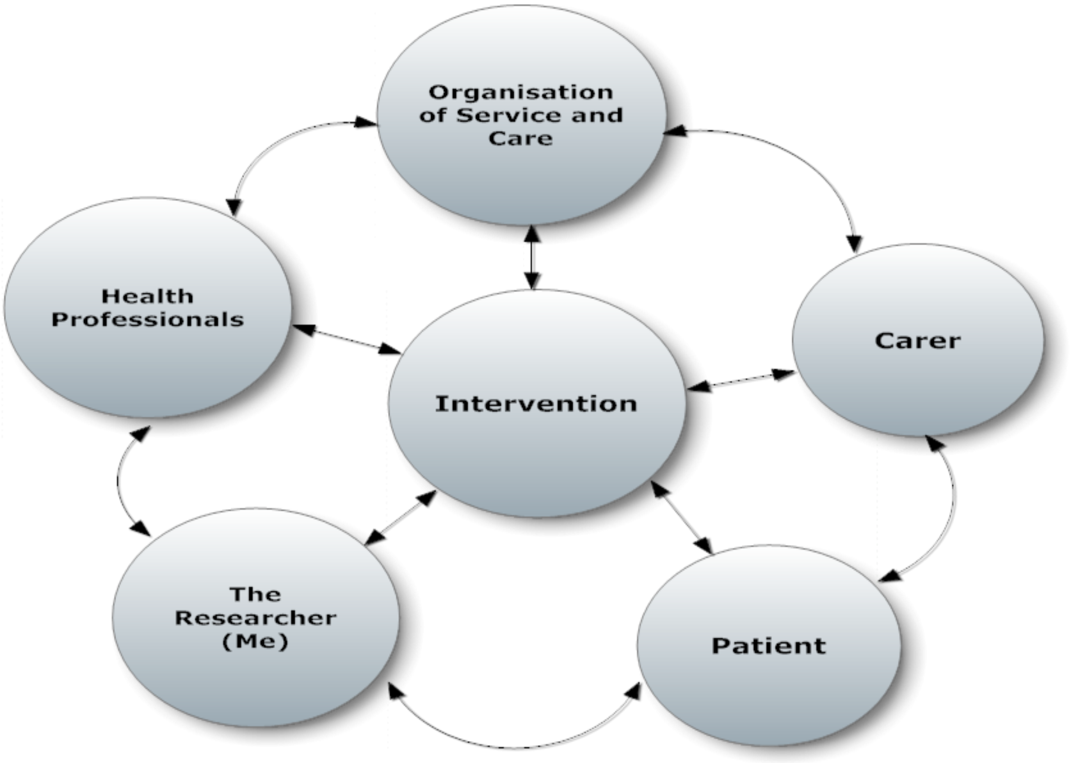


Figure 5: The Five Interrelated Components

3.7.1 Theories of Behaviour Change

When developing interventions it is also necessary to have a theoretical understanding of how behaviours, whether they were organisational or groups of individuals' behaviours, can be changed (Blackwood, 2006; MRC, 2008; Burgess et al, 2009). This is challenging, as there are numerous theories to explain why people and organisations behave in the way that they do and many strategies that can be drawn upon to help change behaviours (French, et al 2012; Grol et al, 2013). Without knowing, which behaviours the intervention aimed to target, it was difficult to know which theory would be the most relevant or useful. There are, however, particularly notable behaviour change theories for example, Bandura's Social Cognitive Theory (1986); and Ajzen and Fishbein's (1974) Theory of Reasoned Action. These theories have a number of overlapping determinants or predictors of behaviour change, which include:

- An intention and readiness to change (motivation)
- The necessary skills and knowledge to perform the behaviour
- Capability and beliefs (self-efficacy)
- Positive attitudes toward the change
- The change fits with the perceived societal and peer 'norms'
- Social/professional role and identity
- The environment is conducive towards change
- Emotions

(Adapted from Fishbein, 2000; and Michie et al, 2008)

These theories are useful for explaining the numerous determinants of change. However, there is little guidance to help map these theories, with strategies for changing behaviours (Francis et al, 2009; Grol et al, 2013). This makes it very difficult for those new to the field of complex intervention research to identify an appropriate behavioural change technique (Michie et al, 2008). Michie et al (2005) using expert consensus methods and systematic reviews, of organisational and psychological behaviour change theories developed the Theoretical Domains Framework (TDF) (French et al, 2012). This framework aimed to simplify and integrate 33 theories and 128 key theoretical constructs of behaviour change determinants (Michie et al, 2008). The original framework identified 12 domains (Michie et al, 2008). A more recent, updated TDF now distinguishes between fourteen domains including: knowledge; skills; social/professional role and identity; beliefs about capabilities; optimism; beliefs about consequences; reinforcement; intentions; goals; memory, attention and decision processes; environmental context and resources; social influences; emotion; behavioural regulation (Cane et al, 2013).

Continuing with expert consensus methods, Michie et al (2008) attempted to map the identified behaviour determinant domains to behaviour change techniques. Over 137 possible techniques were identified. However, agreement was gained for only 35 and of these only 12.2% were thought to be effective strategies. An example, of a strategy which gained high agreement, is that of providing timely feedback to improve beliefs about capabilities. Perhaps more importantly, there was a significant amount of consensus in agreement of techniques that were likely to be ineffective. Michie et al (2008) acknowledged that taxonomies for mapping behaviour change strategies to behaviours, such as the one they were trying to identify, are in its infancy. Nevertheless, Michie et al (2008) provide a useful starting point when developing interventions, helping researchers to think about behaviours and the diverse range of strategies that can be used for changing them.

3.7.2 Theories of Organisational Behaviour

There were also a number of important determinants of organisational behaviour that needed to be considered in more detail for the purpose of meeting the aims of this study. Organisations, as well as being complex adaptive systems, are said to have a culture, which can determine the way it behaves. Schein (1999, p. 111) defines organisational culture *'as (a) a pattern of basic assumptions, (b) invented, discovered, or developed by a given group, (c) as it learns to cope with its problems of external adaptation and internal integration, (d) that has worked well enough to* *be considered valid and, therefore (e) is to be taught to new members as the (f) correct way to perceive, think, and feel in relation to those problems'.* Theories of organisational culture suggest an organisation evolves over time becomes a body of tacit knowledge and values that are hard to consciously describe and once embedded is difficult, but not impossible to change (Grol et al, 2007; 2013). The challenge when introducing a new intervention is that it will need to compete with entrenched and thoroughly 'normalised' ways of working (May et al, 2007). The intervention is more likely to be accepted if it is compatible with the organisation's values (Smollan & Sayers, 2009). Therefore, it is vital when developing interventions to understand and consider how the intervention may interact with the current culture and values of the organisation.

Argyris and Schon's (1978) theories of action and organisational learning can help further explain how organisations learn new behaviours. These theories distinguish between two types of organisational learning, single or double loop learning. Single loop learning occurs when an error is detected within the organisation and actions are taken to remedy the error without addressing the cause (Hayes, 2010). However, the problem with single loop learning is that people's espoused theories of action are not the same as those theories they use in action (Argyris, 1976). In other words, people do not always behave in the way they believe or say they do. In single loop learning the underlying cause is seldom remedied because people are rarely aware without being challenged that there is an incongruity between their actions and beliefs (Argyris and Schon, 1974). Double loop learning, however, addresses the underlying cause by challenging beliefs and values and taking actions to modify behaviours (Hayes, 2010). Effective learning organisations are said to be those that regularly adopt double loop collective learning and are *'characterised by external orientation, experimental mind-set, curiosity about trying new things, a climate in which openness, debate, and conflict are acceptable, on-going commitment to education, growth and development at all levels of the organisation'* (Grol et al, 2013, p. 32).

Rogers (2003) diffusion of innovations theories endeavours to explain how new ideas or changes are spread throughout organisations. According to Rogers (2003) there are four key stages which influence the rate individuals and hence organisations adopt a new intervention: the knowledge stage, which involves learning about the innovation or intervention; the persuasion stage, in which positive or negative attitudes towards the intervention are formed; the decision stage, the acceptability of the intervention is tested; and the final stage, characterised by the adoption or rejection of the intervention. Rogers (2003) also argues one of the most important factors to understand when developing an intervention is the characteristics of the group, which the intervention is targeted towards. Rogers (2003) suggests organisations are made up of individuals who can be classified according to how quickly they adopt new technology and change their behaviour including: 'innovators', those who identify and take forward new ideas, 'early adopters', 'early majority', 'late majority' and 'laggards' those who openly resist change.

It is generally accepted that introducing change within organisational cultures and facilitating organisational learning requires strong organisational leadership (Hayes, 2010; McSherry et al, 2010). Theories of organisational leadership suggest that different types of leadership are required for different types of change (Grol et al, 2013). It is important to establish who the leaders who have the ability and authority to enable and support the proposed change, within an organisation when developing interventions.

3.8 Strategies for Organisational Change

Organisational change strategies generally aim to improve effectiveness by focusing on structures, systems and processes, which enable individuals and teams to deliver an optimal service (McSherry et al, 2010). One cannot write about strategies without acknowledging the social psychologist Kurt Lewin (1890-1947), who emigrated from Germany to America in 1933. His seminal work is said to have had the most impact on the theory and practice of social and organisational change (Kemmis, 1988; Hart and Bond, 1995; Hayes, 2010).

Lewin (1947) proposed the three stage transitional model of change: unfreezing, moving and refreezing. Lewin (1947, 1952) argued change could only occur within an organisation if there was a 'felt need', that is an inner realisation that change is necessary; he defined this as the unfreezing phase (Hayes, 2010). The second is moving, when change is initiated and then finally, refreezing, when the change becomes established as normal working practice (Shanley, 2007; Mitchell, 2013). Hendry (1996, p. 624) suggests *'scratch any account of creating and managing change and the idea that change is a three-stage process which necessarily begins with a process of unfreezing will not be far below the surface. Indeed it has been said that the whole theory of change is reducible to this one idea of Kurt Lewin'.*

However, it is Kurt Lewin's introduction of action research to contemporary social science methodology, which he is most noted for (Kemmis, 1988; Raelin, 1999). Although he wrote only 22 pages on the subject before he died (Dickens and Watkins, 1999), Hayes (2010) contends action research now underpins nearly all organisational change interventions and is a methodology that seeks to 'unfreeze' those who need to adopt new ways of working. Lewin (1946, p.46) defined action research as a form of rational social management, which *'proceeds in a spiral of steps each of which is composed of a circle of planning, action and fact-finding about the result of the action'*. Iles and Sutherland (2001, p.66) who wrote extensively about organisational change within the NHS proposed *'action research is a way of using research in an interventionist way, so that the researcher is both a discoverer of problems and solutions and is* *involved in the decisions about what is to be done and why. It sees organisational change as a cyclical process where theory guides practice and practice in turn informs theory'.* Van de Ven (2007) and Grol et al (2013) describe research which aims to develop interventions as action research.

I would argue that action research as a methodological approach is ideally suited to the initial stages of intervention developmental design, for example, the pre-clinical and modelling phases of the MRC (2008) framework. As identified above, according to Michie et al (2008) one of the main aims of the modelling phase, for example, is to recognise how the intervention could potentially achieve change through an iterative process of experimentation by hypothesising about and testing its various components. Arygis and Schon (1991, p.86) suggest ''*action research takes its cues—its questions, puzzles, and problems—from the perceptions of practitioners within particular, local practice contexts. It builds descriptions and theories within the practice context itself, and tests them through intervention experiments—that is, through experiments that bear the double burden of testing hypotheses and effecting some (putatively) desirable change in the situation'.* Argyris and Schon (1978) also contend that researchers, who take an action research stance are more likely to obtain the participants 'theories in use' rather than their 'espoused theories' as described above, through reflecting together 'on-the-action'. Reflection being a key characteristic of action research (Potvin et al, 2010; Meyer, 1993a). Yet, although extensive searches were performed, no papers were found reporting studies using action research in the early phases of the MRC (2008) framework.

Grundy and Kemmis (1981) and Dickens and Watkins (1999) suggest Lewin's model of action research has two crucial aims, to improve and to involve. However, action research used within organisational management of change has been criticised for having a 'top down' approach, led by managers of organisations rather than having an inclusive participatory or 'bottom up' approach (McTaggart, 1994). Action research as a methodology which endeavours to have active and democratic participation of practitioners and service-users at its core will be discussed in more detail later in the chapter.

3.9 Change and Emotions

Shanley (2007) states the emotional effects on individuals' experience when change is introduced are often downplayed or disregarded by those responsible for initiating and implementing change interventions in healthcare arenas. This can cause a negative impact not just on individuals but also on the success of the proposed change to practice. Schien (1996, p. 29) contends that people when confronted with the notion of change immediately take a defensive stance, because it means they may have to admit they are doing things less than satisfactorily; *'most humans need to assume that they are doing their best at all times and it may be a real loss of face to accept and even "embrace" errors'*.

Healthcare organisations are in a constant and relentless state of flux, usually as a result to pressures exerted by external forces, for example, changes to healthcare policy and increased societal expectations (Shanley, 2007; Iles and Sutherland, 2001). Professionals working in these organisations have to respond to change on a daily basis. They also have to support patients and their families who are themselves, managing the changes illness or disease brings to their lives. Even when change is welcomed or perceived as positive, it can bring with it disruption, uncertainty and defensiveness (Holbeche, 2006).However, as Waterman (1998, p. 102) points out *'paradoxically, although tensions and difficulties in practice may cause discomfort, they motivate change and they are essential to new developments in practice'.* Indeed Huy (1999) states that emotions are a fundamental component of change and adaptation.

Bridges (2004; 2009) argues it is not change itself that causes emotional problems for people; it is the transitions they experience. These transitions Bridges (2009, p.8-10) suggests can be viewed in three often overlapping phases, mirroring Lewin's (1947) theory of transitional change described above. The first stage is ending, this is when the individual acknowledges that something needs to change and they have to let go of the old situation. This can bring about a sense of loss. The next phase he describes as the neutral zone, a '*kind of emotional wilderness'*, which is when everything is in a state of flux, upheaval and uncertainty. Finally, people experience the new beginning phase, when the new situation becomes to feel like the norm. Bridges (2009) contends most organisations try to start with new beginnings, rather than pay attention to the endings and rarely do they consider the neutral zone, which is why he suggests, people will resist change. Other writers of organisational change management have likened the experience of change, because it often evokes feelings of loss, to that of Kubler Ross's (1969) five stages of grief theory; the emotional stages people experience when they are dying (Schoolfeld and Orduna, 1994; NHS, 2005; Holbeche, 2006). The different emotional phases include: denial, anger, bargaining, depression and acceptance.

Most change interventions fail due to the neglect of human emotions (NHS, 2005). Those who are introducing the notion of change should always be attentive to the emotions of those involved and the transitions people experience and negotiate when change is introduced (Bridges, 2009; Shanley, 2007; Jarrett, 2004; Weymes 2002). Furthermore, Schien (1996, p. 29) argues the key to effective change management, '*lies in the various kinds of tactics that change agents employ to create psychological safety'*.

3.10 Knowledge Transfer and Implementation Theories

The failures of research-based interventions to be implemented in practice frequently described as the theory-practice gap have gained increased attention over the last decade from research funders, policy makers, professional leaders and research methodologists (Grol et al, 2013; World Health Organisation, 2012). Within the updated MRC (2008) there is acknowledgement that implementing research designed interventions in complex healthcare settings is a particularly challenging phase, and one that usually requires a separate study or studies. Using passive dissemination strategies alone (e.g. publishing the results), is not enough to ensure interventions are successfully adopted into everyday practice (MRC, 2008; Hack et al, 2011).

To address this problem, there is now an emerging field in healthcare research which focuses specifically on the implementation of research evidence (Eccles et al, 2005; Straus et al, 2009; Davies et al, 2010; Hack et al, 2011; Ryecroft-Malone and Bucknall, 2010). Implementation is defined *'as a planned process and systematic introduction of innovations and/or changes of value: the aim being that these are given a structural place in professionals practice, in the functioning of organisations or in the health care structure'* (ZON, 1997, cited by Grol et al, 2013, p. 10). There are developed and validated implementation frameworks in use. These include: the Knowledge to Action Framework (Graham et al, 2006), Diffusion of Innovations (Rogers, 2003), The Normalisation Process Model (May et al, 2007), Grol's 4 Step Model (Grol et al, 2013) and Promoting Action on Research Implementation in Health Services Framework (PARIHS) (Ryecroft-Malone, 2004; Ryecroft-Malone et al, 2002; 2004b).

Although this study aimed to develop an intervention following the first two phases of the MRC (2000, 2008) framework, it was important to consider theories of implementation. In particular, what prevents (the barriers) and enables interventions to be successfully translated into practice. Attention to these theories from the beginning of the process can inform the development of the intervention by identifying potential design pitfalls and obstacles to implementation (Grol and Wensing, 2004; Legare, 2009; Gitlin, 2013). Baker et al (2010) conducted a systematic review to assess the effectiveness of tailored interventions targeted to change healthcare professionals' behaviours by addressing barriers to change. Twenty-eight studies were reviewed. Barriers in the reviewed studies were identified by exploring the work and perspectives of healthcare professionals through observation, focus group discussions, and interview and survey methods. The findings revealed that tailored interventions were 1.5 times more likely to effectively change professional practice. Although the reviewers concluded that currently there is limited evidence on the most effective approaches to tailoring, including how barriers should be identified and how interventions should be selected to address the barriers (Baker et al, 2010).

Barriers to implementing research based interventions in healthcare exist at many levels including: the patients and carers (knowledge, emotions, self-efficacy and compliance); the individual practitioner and the clinical team (attitudes, emotions, motivation, habits, knowledge and skills); the practice setting (resources, time pressures, environmental constraints, e.g. space); the organisational context (culture, leadership, resources); and external societal, political and economic factors (supporting policy, financial constraints, commissioning and contracting of services) (Grol and Grimshaw, 2003; Hutchinson and Johnston, 2003; Ryecroft-Malone et al, 2004a; Grol et al, 2007; Durlak and DuPre, 2008; Grol et al, 2013; Hack et al, 2011; Gitlin, 2013).

Characteristics of the intervention itself can also impede implementation and these include: perceived limited value or benefit; lack of compatibility or too disruptive to the current working environment or routines; too complex and not easy to explain, understand and use; perceived to be 'risky' with a high degree of uncertainty; financially prohibitive; limited trialability, e.g. difficulties with testing individual components of the intervention; the benefits of the intervention are not visible or easily observed (Grol and Wensing, 2004; Grol et al, 2007; Rogers, 2003). Another critical barrier includes not having a facilitator who is able to 'champion' or assume responsibility for the implementation of the intervention within clinical practice (Ryecroft-Malone et al 2004a; Hack et al, 2011).

3.11 Approaches to Involving Others in Research

From the discussion above it is evident to develop an intervention which aims to address complex social problems, such as the one this study sought to do, is a complex undertaking. Many factors need to be considered. However, there appears to be an essential ingredient that should be present throughout the developmental process. As well as tailoring the intervention to identified barriers, a vital factor for ensuring the intervention is feasible and of value is to involve those who will be the end-users from the beginning of the design process (Denis and Lomas, 2003; Van de Ven, 2007; MRC 2008; Hack et al, 2011; Grol et al; 2013).

The aspiration from the beginning of this study was to use an approach incorporating a participatory research methodology. However, as Reason (1994, p. 3) warns 'it *is terribly easy to espouse participation and yet at times incredibly difficult to practice genuinely'*. Nonetheless, he argues it is not impossible. However, involving others in research can add another layer of complexity and requires researchers to have particular skills, values and attitudes (Van de Ven, 2007; Stringer, 2007). The next section will explore the current strategies and rationales for involving others in research.

3.11.1 Involving Others in Research: Engaged Scholarship

Van de Ven and Johnson (2006) assert there are fundamentally two problems prohibiting the use of research evidence in practice. One is to do with how interventions are transferred or implemented (described above), and the other they describe as a knowledge production problem. Schon (1991) recognised the gap between knowledge derived through research and the practice-based knowledge used by practitioners. He described it as: *"in the varied topography of professional practice, there is a high, hard ground where practitioners can make effective use of research-based theory and technique, and there is swampy lowland where situations are confusing "messes" incapable of technical solution. The difficulty is that the problems of the high ground, however great their technical interest, are often relatively unimportant to clients or to the larger society, while in the swamp are the problems of the greatest human concern"* (Schon, 1991, p. 42).

Van de Ven and Johnson (2006) and Barge and Shockley-Zalabak (2008) argue that academics must make research more relevant to practitioners by establishing meaningful engagement with them; accomplishing this will help bridge the gap between theory and practice. Van de Ven (2007) proposes a different approach to research, one he terms 'engaged scholarship'; defined as: *'a participative form of research for obtaining the different perspectives of key stakeholders (researchers, users, clients, sponsors and practitioners) in studying complex problems. By involving others and leveraging their different kinds of knowledge, engaged scholarship can produce knowledge that is more penetrating and insightful than when scholars or practitioners work on problems alone'.* (Van de Ven, 2007, p.9).

McCormack (2011) points out, for those who are conversant with action research methodology, an engaged scholarship approach might appear to be nothing new. However he states *'whilst recognising the importance of action research as a well-established approach to engaged scholarship, Van de Ven's (2007) approach makes the case for principles of engagement to underpin all research methodologies and for this to be an explicit criterion in the establishment of research designs'* (McCormack, 2011 p. 116). Van de Ven (2007) uses the term 'scholarship' rather than research intentionally. He quotes Pettigrew (2005) who argued scholarship is more than conducting good research; it includes a responsibility to make research findings accessible through learning, teaching and engagement. Van de Ven (2007, p. 10) proposed the engaged scholarship diamond model (Figure 6 below), which he suggests should inform all types of research designs. The degree of engagement depends on the purpose of the study.

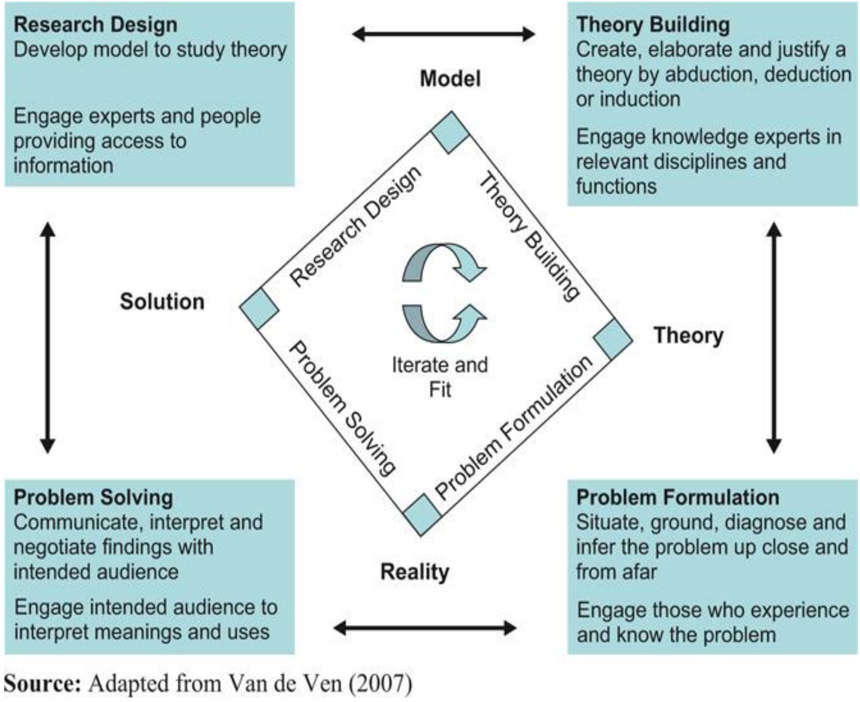


Figure 6: Engaged Scholarship Diamond Model

3.11.2 Involving Others in Research: Patient and Public Involvement (PPI)

In the last decade there has been considerable movement in the Department of Health and the NHS towards involving the general public and patients in healthcare policy, research and service delivery development (Attree et al, 2010; Brett et al, 2012). Indeed the Department of Health (2005b, p.5) proposed *'to move from a service that does things to and for its patients to one which is patient led, where the service works with patients to support them with their health needs'.*

This vision for patient-led services has inevitably impacted on healthcare research in the UK. In 2006 the Department of Health (DH) outlined, within a policy document entitled 'Best Research for Health: A New National Health Research Strategy', how involving patients and the public will ensure that research *'is more relevant to people's needs and concerns, more reliable and more likely to be put into practice'* (DH, 2006, p. 34). Since then healthcare research funding bodies, for example, the National Institute of Health Research (NIHR) and the Medical Research Council (MRC), demand researchers actively involve the public and patients within their work; not just as research subjects but as active contributors to every stage of the design and process of the study (Brown, et al 2006). Entwistle et al (1998) suggests there are two reasons why involving lay people should become an imperative in healthcare research. The first has already been highlighted, the insights and knowledge lay people have can complement those of healthcare professionals and researchers. Entwistle et al (1998, p.463) also argues there is a politically mandated reason, *'prevailing notions of democracy suggest that the public, as the "owners" of publicly funded research, should have a say in what is done and how'.*

Patient and public involvement (PPI) also described as user involvement, can include individuals and groups as described Table 6 below. INVOLVE, a UK NIHR organisation, which promotes and supports service user involvement in designing and evaluating research, suggests involvement can occur at three different levels including: consultation, for example, passively providing advice, collaborative, for example, more direct involvement by influencing and providing feedback about the design or findings and user controlled research, for example, service users design, undertake and disseminate the findings (INVOLVE, 2012). The most common approach for involvement is consultation and 'user-led' health-care research is rare (Morrow et al, 2012).

Table 6: Individuals and Groups who may be Considered 'Service Users'

Individuals		
Patients	**Local Groups**	
Clients	Patient Groups	**(Inter) National Organisations**
Service Users	Population Groups	
Survivors		Statutory Bodies
Potential Service Users	Faith/Cultural Groups	
Carers	Ethnic Groups	Charities
Relatives	Social Groups	Support Groups
Families		Lobby Groups
	Support Groups	
Representatives	Interest Groups	Patient/Professional Alliances
Advocates	Carer Networks	
Citizens		
Members of the Public		

(Adapted from Morrow et al, 2012 p. 21)

Morrow et al, (2012) suggest achieving meaningful involvement with service users throughout the whole research process is challenging and not always feasible. However, various approaches can be used at different stages dependent on the nature of the research. Service users for example have been involved in trial research to enhance recruitment and design more accessible trial information; while in qualitative research service users can help researchers, design language appropriate interview schedules and avoid missing subtle differences in lay and professional language when analysing the findings (Morrow et al, 2012, p. 46).

Genuinely involving lay-people in the research process, so that is meaningful and beneficial for all, is time consuming. It requires significant input from researchers; they need to identify and recruit willing people, develop relationships, and create opportunities and space for involvement and collaborative activities (Cook, 2012; Morrow et al, 2012). Involving lay-people in research is not a one-off activity, it is a process. However, researchers are required to meet strict deadlines to satisfy funding bodies. This can significantly affect how much time they have to really involve people during a project. Frequently service users have little research experience or knowledge and terminology can be a significant barrier (Shippee et al, 2013). Incorporating training for service users to enable meaningful engagement can significantly impact on the researcher's time and be costly. Financial constraints can also create barriers (Cook, 2012). Current guidance provided by INVOLVE, recommends that service-users should be paid, in recognition of their time and expertise (INVOLVE, 2012). Although most research funding bodies within healthcare now expect researchers to budget for this in applications for funding, not all do.

Researchers may need to change the way they conduct research and until recently there have been few available training opportunities to help them adopt the skills required for working with service-users (Morrow et al, 2012). However, as highlighted previously, one of the biggest barriers to service user involvement is the attitudes of researchers, who may not want to work with lay people, or respect their expertise and believe that involvement offers little benefit (Morrow et al, 2012; Van de Ven, 2007; Hubbard et al, 2007). It is these limitations and constraints that have led to some suggesting that service-user involvement can be a tokenistic activity used increasingly to appease research funders (Morrow et al, 2012; Fox et al, 2007; Staniszewska et al, 2007).

3.11.3 Involving Others in Research: Action Research

It could be argued that all research is a collaborative activity and requires the involvement and contribution of others (Hallowell et al, 2005). In traditional research paradigms, this usually entails the involvement of others as 'subjects' to be researched, for example, interviewing people. However, action research differs from conventional quantitative/qualitative research paradigms. Researchers using this approach actively seek to have others, for example, practitioners and service-users, participate within the research process, to co-produce new knowledge. Action research, therefore, shares the same overarching goal as all research paradigms, that is, to gain fresh insights and generate new knowledge (McNiff and Whitehead, 2011; Stringer, 2007). Thus, action research values developing and using existing theory. Where it differs to conventional research paradigms, is that new knowledge is created about social situations through introducing for example, new ways of working and then seeking to understand how and why change or improvements to practice have occurred, with those the changes impact upon (McNiff and Whitehead, 2011; Meyer, 2006).

However, action research can be difficult to define and complex to use (Waterman et al, 2001). Since Lewin's (1946) seminal paper (discussed previously) action research methodology has evolved, initially embraced by educationalists, organisational change management and more recently health and social care research (Hockley and Froggatt, 2006). Hart and Bond (1995, p.14) suggest that action research has developed from '*an Americanised form of rational social management to a more robustly democratic and empowering approach to change'*. There is no definitive and agreed approach to action research, and confusingly there is debate still on the origins of action research. Indeed, action research appears to remain an umbrella term for an assortment of methodologies used to promote change (Dickens and Watkins, 1999; Hockley et al, 2013).

Munn-Giddings et al's, (2008) systematic review of the uptake and design of action research in published nursing research, 2000-2005, revealed 24 different terms used to define action research. The diversity of terms and definitions included: collaborative action research, emancipatory and participatory research and evaluative research. Other authors have also noted different terms used to define action research including: co-operative inquiry, action science, action learning and a recent addition appreciative enquiry (Koshy et al, 2011; Williamson et al, 2012). It can be seen from these terms that there are types of action research, which seem to differentiate between action research and participatory action research. McNiff and Whitehead (2011, p. 12) argue this creates confusion and could be viewed as pointless, because action research is by default participative and inherently collaborative. While Reason and Bradbury (2001, p. 2) contend *'action research is participative research and all participative research must be action research'*. Yet, it is apparent that how action research is defined and applied depends on a number of important factors including among others: the philosophical, epistemological, ideological basis and purpose of the research (Williamson et al, 2012; Potvin et al, 2010; Reason and Bradbury, 2001; Raelin, 1999).

Different authors have attempted to differentiate between the plethora of approaches and various philosophical assumptions underpinning action research. Grundy (1982, pp. 23-34) for example, uses Habermas's (1972) three domains of knowledge, to describe three modes of action research: 'technical' 'practical' and 'emancipatory'. Grundy (1982) then draws upon Aristotle's notions of human action to explain the differences between each approach. In the technical mode, researchers would adopt the position of ‘craftsmen’ or experts who have the ideas about what needs to change and will use participants to help them implement these ideas. In the ‘practical’ mode, researchers are guided by ‘phronesis’ broadly defined as personal wisdom. In this mode researchers *‘will seek to improve practice through the application of the personal wisdom of the participants’* and knowledge is developed through language, communicative and hermeneutic interpretation. Finally researchers working within the ‘emancipatory’ mode would seek to enable participants to become aware of and free themselves from oppressive constraints imposed by the organisations and systems they are working or living within. This mode relies on all those involved to have a critical intent, which is ‘*the disposition which enables the development of ‘theory’ with personal judgment (phronesis) by the process of reflection’* (Grundy, 1982 p. 359).

Whitelaw et al (2003) also differentiate between three types of action research: technical-scientific which is influenced by positivist worldviews (the technical mode); secondly, mutually-collaborative (the practical mode) underpinned by the interpretivist paradigm; and finally critical and emancipatory modes of action research, which draw upon critical theory and most notably the Frankfurt School and writings of Habermas (1972). Other authors recognise the important contributions of the Brazilian Paulo Freire (1970) who believed that people should be empowered and liberated through education; and feminist theories to the philosophical discourse of emancipatory action research (Cresswell, 2013; Green and Thorogood, 2009).

Perhaps the best known classification of action research in nursing is the typology presented by Hart and Bond (1995, p.37-38). They contend that action research has seven criteria which distinguish it from other research paradigms, including:

1. *It has an educative base;*
2. *It deals with individuals as members of social groups;*
3. *It is problem-focused, context specific and future orientated;*
4. *It involves a change intervention;*
5. *It aims at improvement and involvement;*
6. *It involves a cyclical process in which research, action and evaluation are interlinked;*
7. *It is founded on a research relationship in which those involved are participants in the change process.*

Hart and Bond (1995; 1996) suggest that these criteria have different appearances and vary within what they describe as the four types of action research including: ‘experimental’, ‘organisational’, ‘professionalising’ and ‘empowering’. They acknowledge however, that inevitably action research projects evolve and vacillate between types. Action research requires researchers to be flexible in their approach and to expect the unexpected. As in the case of Kelly and Simpson (2001, p. 653) who used this approach to introduce clinical practice facilitators into an acute hospital setting. They acknowledged that initially the *'primary focus could have been considered organizational in nature. As the work progressed, however, it became necessary to shift towards a more professionalizing or empowering approach to support the individuals concerned to establish the role. It also became clear that significant change could only be achieved in the organization by developing the individuals themselves'.*

Regardless of the philosophical foundations Meyer (1993a; 2010) contends that Lewin's basic action research model a cyclical or spiralling process of planning, acting, observing and reflecting still underpins all forms of contemporary action research. Stringer (2007) suggests a slightly different alternative process that of continuous cycles of looking, acting and thinking. Action researchers can draw upon both qualitative and quantitative methods to gather data within these cycles, however qualitative research usually predominates (Stringer, 2007; Waterman et al, 2001). While there are many different approaches and methods, Reason and Bradbury's (2001, p. 1) definition appears to encapsulate what action research is: *'a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities'*

Reason (1994) suggests that you need to develop your own approach for action research and involving others, and there is no right or wrong way of doing this type of research. However, action research should always be conducted systematically, rigorously, and ethically (Stringer, 2007).

3.11.4 The Criticisms and Challenges of Action Research

Action research has frequently been misconstrued and unappreciated for the contribution it can make as an approach to inform knowledge and develop practice. Critics of action research suggest it is not scientific research, but practice development (Gelling and Munn-Gidding, 2011; Meyer, 1993a). There is in principle very little difference between the two, action research after all aims to inform, develop and change practice. Meyer (2006, p.279) argues that the two are subtly different; it is research *'if systematic rigour is applied and findings are to be shared with an audience outside the study's context then this constitutes research and the usual systems of research governance and ethical approval apply'.* Yet, frequently action researchers struggle to get ethical review or approval for projects from NHS Research Ethics Committees (RECS) due to the conflicting opinions of what action research is (Gelling and Munn-Gidding, 2011). Furthermore, the changing and unpredictable nature of action research means it is at odds with stringent ethics committees' requirements for transparency. This confusion has also impacted on action research projects being funded (Russell, 2013).

The ethical principles underpinning action research are the same as for all social research. Above all, those who are involved in the study should be protected from harm (Meyer, 2010; Stringer, 2007). Conducting research ethically means participants have the right to confidentiality and anonymity, being informed and providing consent, to be treated with honesty and integrity and finally they have the right to not participate or be able to withdraw from the study (Williamson et al, 2012). There are however, a number of ethical issues that are particularly pertinent to action research that should be taken into account. Williamson and Prosser (2002, p. 589) pose three important ethical questions, which need to be considered throughout action research projects:

1. *How can anonymity and confidentiality be assured when the researcher and participants are working so closely together?*
2. *If action research study is a 'journey; and 'evolves', how can informed consent be meaningful?*
3. *As action research can have political consequences, how can the researcher avoid doing harm to the participants?*

While action research relies on the collaboration of others, it would be unethical to coerce or manipulate participants into taking part. This may create difficulties for the researcher and the participants, if for example, funders, managers and the organisation want the research to be conducted. Participants may find it difficult to decline and feel obliged to participate. Informed consent, therefore, needs to be carefully considered, negotiated, and repeatedly reconfirmed with study participants (Meyer, 2010). The notion of who holds the power and is responsible for initiating the study and the decision-making is an important one for action researchers (Schein, 2001). If the researcher is perceived to be an 'expert' by participants, to have more knowledge about the subject and control over the research agenda, it can destabilise the democratic process and leave participants feeling threatened (Williamson et al, 2012).

The researcher's association with the research site can also create challenges. The limitations (and also benefits) differ depending on whether the researcher is considered an 'insider' or 'outsider'. Insiders are generally those that have a position within the organisation and who can be viewed as ‘one of us’. Whereas outsiders are those from external organisations and are usually change consultants or academics working within higher education institutions (Fox et al, 2007; Allen, 2004; Waterman et al, 2001). Having insider knowledge of the research site would seem preferential when doing this type of research, the researchers already have a relationship with participants and an understanding of the culture they are researching (Waterman et al, 2001; Bonner & Tolhurst, 2002). However, insiders may be over familiar with the setting or situation and as result unable to be critical and question embedded ways of working or cultural tacit knowledge (Bonner and Tolhurst 2002). Outsiders are likely to bring ‘*fresh perspectives’* but they will require more time to access and understand the research setting, and develop rapport and working relationships (Waterman et al, 2001, p.23).

3.12 The Quality of Qualitative and Action Research

Critics of action research suggest it is difficult to determine the quality of the research and question whether findings can be valid and reliable (Fox et al, 2007; Waterman et al, 2001). Indeed action researchers, until the 1980s, tended to evaluate projects using quantitative/positivist criteria for evaluating quality and rigour (Stringer, 2007). Researchers using quantitative methods need to demonstrate objectivity, reliability, validity and generalisability. However, in action research where much relies on the subjective nature of participation and involvement these measures are frequently inappropriate or unachievable (Waterman, 2001). Conversely, validity in action research has been defined as whether those reading the research find it to be truthful and appropriate (Williamson et al, 2012). Waterman (2001) poses twenty questions to provide guidance for assessing action research proposal and projects. Stringer (2007) suggests using the criteria for assessing qualitative research as outlined by Lincoln and Guba (1989); these include the following attributes: credibility, dependability, confirmability, transferability (Table 7 below).

Table 7: Strategies to Enhance Rigour

Approach	**Purpose**	**Strategy**
Credibility	Determine how plausible the findings are and the integrity of the study	• Prolonged engagement and persistent observation • Triangulation • Peer/expert/participant debriefing • Diverse case analysis • Member Checking • Referential adequacy – the findings and terminology used is easily understood
Dependability	Is similar and relates to the concept of ‘reliability’ and	• Audit Trail • Reflexivity

Approach	Purpose	Strategy
	whether the research procedures used stand up to scrutiny	
Confirmability	Evidence that the procedures used actually took place – to confirm the 'veracity' of the study (very similar to dependability)	• Audit Trail • Reflexivity
Transferability	The extent to which the findings may be relevant and applicable to areas outside the research site	• Enough detailed information is provided, often through the provision of 'thick descriptions' in order to help others make informed decisions about whether the findings can be transferred

Adapted from: Guba and Lincoln, 1989; Houghton et al, 2012; Stringer, 2007.

While there continues to be an on-going debate on the philosophical and practical underpinnings of action research, nearly all writers appear to agree when undertaking this type of study that researchers must engage in critical reflection and reflexive practice. There remains a lack of consensus on definitions and practices of reflexivity in action research, or indeed all social science research (Potvin et al, 2010). Critical reflection has been defined by Fook et al (2006, p. 12) as a process by which '*adults identify the assumptions governing their actions, locate the historical and cultural origins of the assumptions, question the meaning of the assumptions, and develop alternative ways of acting'.* Reflexivity is a term generally used in social research and can simply mean '*a researcher's acknowledgment that they have had an impact on the research setting, and the setting has also had an impact on the researcher'* (Williamson et al, 2012, p. 241). There are criticisms of engaging in reflexive practice as Breen (2007, p. 170) describes, *'it is often seen as narcissistic and navel gazing; the belief that it has the potential to undermine the legitimacy of the research and researcher.'*

The confusions and misunderstandings surrounding what action research is and does, and the complexities and challenges using this methodology inevitably create, is perhaps the reason why research reports of studies were not found, which integrated the early phases of the MRC (2008) framework with action research. However, this may soon change as attitudes towards action research appear to be shifting, perhaps because of the failings of research being implemented into practice (Meyer, 2010). A recent newsletter published by the London NIHR Research and Design Services extolled the virtues of action research, and asked *'what is not to like about action research?'* (Russell, 2013 p.2).

3.13 Overview of the Study

As previously stated I wanted to use a research methodology that would enable a creative co-production of knowledge with those that would be the ‘end-users’ of the intervention. As Meyer (2010, p. 258) states ‘*too much research is built around the researcher as expert, with a ‘hit and run’ approach to data collection’*. Wishing to avoid doing research ‘on’ or ‘for’ people by actively seeking to engage people in the process (Hockley and Froggatt, 2006); as it was thought adopting this approach would provide a more insightful understanding of the needs of carers and how these could be feasibly met by practitioners in the treatment setting.

In light of the previous discussion, an action research approach would seem ideally suited to meet the aim and objectives of this study. Yet at the beginning of this project I had profound reservations about describing the methodology as participatory action research. This is because as Greenwood et al (1993, p.176) states: *‘no-one may mandate in advance that a particular research process will become a fully developed participatory action research project. Participation is a process that must be generated. It begins with participatory intent and continues by building participatory processes into the activity with the limits set by the participants and the conditions. To view participation as something that can be imposed is both naïve and morally suspect’.*

This study, therefore, started with an engaged scholarship and participatory intent, orientated towards change and action (interventions), which evolved, in the modelling phase, into an action research project. It should be noted that this evolution only occurred because most of the participants wanted to address the problems and develop their practice in this area.

3.14 Pre-Clinical Phase: Formulating the Problem

To recap, the overall aim of this study was to identify and develop interventions to enable healthcare professionals to prepare and support family and friends (carers) in the chemotherapy setting. The findings, from the review of reviews, revealed that no interventions had been developed which focused on the specific needs for carers in the chemotherapy setting. Of those that had been developed more generally across the cancer trajectory, few were well described, many had significant methodological flaws. While some studies were found to use theory, such as Lazarus and Folkman’s (1984) theory of stress and coping, little information was given to how these theories were used. None had explicitly drawn upon theories of behaviour or organisational change to underpin the design of the intervention. Another important review finding was practitioners’ experiences and needs for effectively supporting carers in cancer settings had been largely overlooked. Further database searches were conducted to ascertain whether healthcare professionals’ experiences of working with carers had been explored in other healthcare settings. Very little empirical work was found that had addressed this topic. This was a major omission (among others) in this field of research. As highlighted above, this understanding is imperative if research-based interventions are to be successfully translated into practice.

The pre-clinical phase aimed to meet the first three objectives of this study, as a reminder these were:

1. Describe how healthcare professionals prepare and support carers in the chemotherapy outpatient setting and identify any unmet needs.
2. Identify carers' perceived needs for role preparation, information and support, when supporting patients through chemotherapy.
3. Identify healthcare professionals' perceptions of carers' needs, how they perceive these are and should be addressed and their perceptions of the barriers and enablers to supporting carers.

To meet these objectives an engaged scholarship approach (Vane de Ven, 2007) was undertaken, to gain an understanding of the problems currently faced by practitioners and carers in the chemotherapy treatment phase. Although some preliminary research in this area had been conducted (Ream et al, 2010) a further exploration of the nature and level of carer involvement during treatment was required. The findings of the review of reviews suggested that carers had significant unmet supportive care needs. Yet why this occurred in clinical practice was not clear. This needed to be determined. As previously discussed, it is also necessary when developing interventions to understand what might prevent them from being implemented into clinical practice and how any identified barriers may be overcome. Therefore, the pre-clinical phase was important for:

a. Identifying and engaging with key stakeholders and probable end-users of the interventions.
b. Diagnosing and formulating the problems from the perspectives of all those that would be the end-users of the intervention.
c. Establishing a theoretical understanding of the behaviours the intervention aimed to target and how this might be done.
d. Establishing the barriers and enablers of supporting carers and implementing change in the chemotherapy setting.
e. Building collaborative relationships and generating participation for the next phase of the study (the modelling/action phase).

The pre-clinical phase was based on a qualitative, exploratory, inductive design, which aimed to build theory rather than test it. Within this phase my primary role was to collect any data that was deemed to be potentially useful to help formulate the problem and make sense of what was currently happening within the research settings and further afield. To do this qualitative fieldwork data collection methods of participatory observation and interviewing were used; because as Pope and Mays (1995) suggest people '*are complex and should be studied by watching them, joining in talking, and reading what they write'*.

The principles and techniques underpinning qualitative fieldwork, and in particular ethnographical methodology, greatly influenced how I conducted myself and the data collection methods within this phase. For two reasons, firstly ethnographic methods generally are the most *'naturalistic in that they attempt to generate in-depth knowledge about a setting, over time, in order to understand how and why people believe and behave as they do'* (Green and Thorogood, 2009 p.22). Ethnography is extremely useful for understanding the organisation and culture of the healthcare service (Savage, 2000a). Ethnographers seek to reveal the 'emic' or insider view of members of the culture, by becoming immersed in the setting they are studying (Holloway and Todres, 2010; Lofland et al, 2006). Secondly, participatory observation is often considered synonymous to ethnography and most guidance written for participatory observation stems from anthropologists and ethnographic researchers (Bryman, 2008; Pope and Mays, 2006; Savage, 2000b; Spradley, 1980).

Ethnographic fieldwork is a flexible and iterative approach but again this does not suggest there is a lack of rigour to the process (Allen, 2010; Fetterman, 2010). Similar issues relating to the position of the researcher, ethical predicaments and the quality and trustworthiness of the research, as discussed above, apply to qualitative fieldwork. However, there are fundamental differences between the underlying philosophies of ethnography and participatory research. Participatory methodologies have an explicit intention to involve others and enable change. Conversely, in ethnographic fieldwork there is high involvement of the researcher within the site but participant involvement and decision making within the research processes is low (Schein, 2001). Qualitative researchers in an attempt to gain a naturalistic understanding strive to leave little imprint or avoid creating change within the research setting. Though, arguably this is unachievable (Bryman, 2008). As Green and Thorogood (2009, p.23) contend *'any act of observation will impact on the field, however invisible the researcher becomes'*. Therefore, researchers using qualitative research methods must also be critically reflexive, and account for how their presence may have impacted. Nonetheless, it can be seen that using qualitative methods, such as participatory observation, while adopting a participatory approach has the potential to create tensions (Waterman et al, 2001).

3.15 Modelling Phase: Moving from Analysis to Action

This phase predominately aimed to meet the next three objectives of this research study:

5. Develop with healthcare professionals and carers, components of an intervention to prepare carers for, and sustain them in, their care-giving role when supporting people receiving chemotherapy.
6. Assess the feasibility and acceptability of the intervention/s.
7. Identify the training and support required by healthcare professionals to engage with and support carers.

The modelling phase was underpinned by the principles and practices of action research, which commenced with two workshops, one held on each site. The findings presented at these workshops acted as a catalyst, triggering participants into action (Stringer, 2007). A spiralling process of planning, acting, observing and reflecting followed.

3.16 Chapter Summary

In this chapter it has been outlined how and why this study started with an engaged scholarship and participatory intent, orientated towards change and action (interventions), which developed, in the modelling phase, into an action research project. The methodology evolved as I began to understand more about the complex nature and theory of developing research-based interventions, which essentially are aimed at changing both individual and organisational behaviours. An understanding of change management and implementation theory is, therefore, imperative when developing research-based interventions. Furthermore, if the intervention is to be feasible and beneficial, researchers must actively seek to involve those who will ultimately be the ‘end-users’ of the intervention throughout the process.

Chapter 4 Methods

'I keep six honest serving-men
(They taught me all I knew);
Their names are ***What*** *and* ***Why*** *and* ***When***
And ***How*** *and* ***Where*** *and* ***Who*****.**
I send them over land and sea,
I send them East and West;
But after they have worked for me,
I give them all a rest.'
Kipling R (1902)

4.1 Introduction

This chapter will initially describe the specific methods and how they were used within the pre-clinical phase, which could also be described as the problem formulation phase (Van de Ven, 2007). A number of different data collection methods were used, including: a systematic review of pre-existing reviews (Chapter 2), participatory observation, basic audits and formal interviews with healthcare professionals, carers and patients.

In the modelling phase components of a complex intervention were developed using action research methods. A brief overview of these will be provided, however, a further more detailed description of these methods will be presented in Chapter 7.

4.2 Beginning the Process of Involving Others

At the start of this study, two project advisory groups were established.

4.2.1 The Carer Advisory Group

The first, a carer advisory group consisted of eight people who had experience of caring for someone who had received chemotherapy. They were recruited from a previous carer study, for which I had been a co-applicant and investigator (Ream et al, 2010). The group was convened to support this PhD study and other projects the research team were undertaking. I had the role of Chair and was responsible for the management of this group.

The original group consisted of an eclectic group of people, including a retired policeman, a chaplain, two housewives, a retired nurse, a legal executive, and two office workers. Seven of the eight were females. Five were caring for their partners/spouses. Of the two others, one was looking after her father, while the other was a carer for her young adult daughter. Members also included five researchers who worked in the university, of these three came from a nursing professional background.

When this group was first convened, members' participation and involvement could be described as 'passive consultation' (Morrow et al, 2012). The researchers would present their work and the carers would comment or provide advice. However, this level of involvement proved unsatisfactory for everyone. The group together considered how these meetings could be facilitated to maximise meaningful collaborative engagement. Working rules and 'Terms of Reference' were established. A small annual stipend was offered as an acknowledgement of time and input. Travel expenses were reimbursed for those who wanted it. However, a number of members refused any money as they were retired (payment had tax implications) and had free travel permits.

Although this had not been required by the ethics committee (REC), the need to maintain confidentiality was highlighted at every meeting. One of the members suggested the group incorporated and abided by the 'Chatham House rules' as follows: *'When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed'*, (Chatham House, 2013).

Formal meetings were convened twice a year, usually in September and March. They were held between 1-3pm with lunch provided throughout the study. Between meetings a 'newsletter' was sent to the members, reporting progress with work, how their input had helped and opportunities available for attending training or other events. Indeed three members (including myself) attended a study day specifically aimed to provide training for enhancing patient and public involvement (PPI) in research, held at the local regional cancer centre.

Members from this group were regularly contacted throughout the study. They were asked for advice about specific issues that arose during each stage. Members, for example, provided guidance about how to approach participants when seeking informed consent for participatory observation and interview purposes. They also reviewed and informed the interview topic schedules and how to pose some of the questions asked in the interviews. Some questions, especially those considered potentially sensitive, were discussed in detail. Their involvement, however, increased considerably during the modelling phase when components of the intervention were being developed.

4.2.2 The Project Advisory Group

A second group was established. This was a project advisory group consisting of key stakeholders. Members of this group came from the research site, the university, the regional cancer network, primary care trusts, voluntary organisations and known experts in the field. Members included three nurse consultants, two senior medical oncologists, and a network nurse director, two lead cancer nurses, researchers, advanced communication skills facilitators, and a service development facilitator. This group also included two patients and two carers who were also members from the carer advisory group. While most advisory group members were involved throughout the study, the contribution from different members of this group fluctuated. Some members for example, were contacted for specific guidance on particular issues and therefore, collaborated for either a single meeting or a short period. Healthcare professionals who worked within the primary care were also contacted and met with (two GPs and District Nurses), from palliative and mental health settings to gain an alternative understanding of the patient/carer experience.

At start of the project many of the stakeholders and advisors were met with on an individual basis. At these meetings information about the study was given and useful guidance was received. Findings were reported to members of this group, either in a group setting or to individual members, at regular intervals throughout the duration of the study. This aided interpretation of the data and provided guidance for constructive modifications to study procedures.

4.3 Study Context and Setting

The primary research settings throughout this study were two cancer units (Site 1 and Site 2) each providing chemotherapy treatments in chemotherapy day units (CDU) within one NHS Trust. These settings were chosen because there was an established relationship with the Trust and considerable organisational support both from management and many staff members. Senior clinicians who worked within the Trust had acknowledged that their cancer services need to be more supportive of carers. However, they were unclear on how best to achieve this.

4.4 Pre-Clinical Phase: Ethical Considerations

Before starting the study, I was aware I would be working with patients and carers during a difficult time for them. Therefore, potentially there could be issues of participant vulnerability, informed consent and maintaining confidentiality. These issues needed careful consideration throughout the project. Informed consent was repeatedly sought at every stage of the study.

Members of the carer advisory group advised that carers and patients would be concerned, either by participating or not participating in this study, that they might jeopardise the patient's treatment (Holloway and Todres, 2010). During the fieldwork, both carers and patients were assured that the patients' care would not be affected. It was made clear to all patients and carers that their involvement was entirely voluntary. Participants had the opportunity to withdraw from the study at any stage without any repercussions or prejudicing the patients' care. All information obtained about participants was anonymised and written information was stored in locked cupboards or on password secured, encrypted computer files.

Participating in this study may have raised some ethical issues for healthcare professionals. Staff might have felt their work was being scrutinised and this may have left them feeling vulnerable. There could also have been issues around confidentially, informed consent and voluntary participation (as opposed to being coerced) for healthcare professionals. Healthcare professionals involved in the study were told that participation was entirely voluntary; they had the opportunity to withdraw from the study at any stage without repercussions and some did. They were also reassured that any information obtained would be anonymised and stored appropriately. Maintaining anonymity was made easier by having two sites involved. They were also made aware that as a registered nurse I was also bound by a professional code of practice to intervene if I observed or came across practices that would comprise patient safety and care (NMC, 2008).

Ethical approval was sought via the Integrated Research Application System (IRAS) originally for the pre-clinical phase. A table outlining all documentation submitted to the research ethics committee (REC) can be found in Appendix 3. Favourable opinion was given by the East Central London REC1 committee (L11/lo/0212) (Appendix 4). Subsequently, the Trust's research and development (R&D) committee also reviewed and approved the study. Two substantial amendments to the original application were subsequently applied for (to be discussed later) and these were approved by both committees.

Applying for ethical approval generates a lot of paperwork. Study documentation, for example, invitation packs supplied to the different groups of participants, which contained an invitation, study information sheets and consent forms, produced 63 pages. Therefore, only examples of this documentation have been provided in the appendices.

4.5 Pre-Clinical Phase: Fieldwork Data Collection

Although fieldwork data collection and analysis was iterative, occurring simultaneously throughout the pre-clinical phase of the study. For clarity how they were conducted will be explained separately through four steps:

Step 1: Participatory observation.

Step 2: Interviewing carers.

Step 3: Interviewing patients.

Step 4: Interviewing healthcare professionals.

4.6 Step 1: Participatory Observation

Observational research methods are useful when trying to understand how organisations and services work; and the roles of and relationships between staff and service users. Participatory observation is also useful to explore whether people behave in the way they say they do (Mulhall, 2003). Using this method, an understanding of how carers' interacted in this setting and the current levels of support carers received from practitioners was obtained (Bowling 2009).

Savage (2000a) and Allen (2010) describe participatory observation as becoming involved in everyday activities of those being studied. Researchers can assume one of four different roles, when using observation as method of data collection. These roles range along a continuum from complete participant, participant-as-observer, observer-as-participant to complete observer (Kawulich, 2005). While in the CDUs my predominant role, was that of participant-as-observer. This role was similar to that of a healthcare support worker, helping staff with tasks while observing. For the observations I wore a nursing uniform, which was different to the uniforms worn by nursing staff at the Trust (the tunic was a lighter shade of blue) and a name badge, which clearly identified me as a nurse researcher. Throughout the study, I consistently introduced myself as a 'nurse researcher'.

At the beginning of the study, I was neither an 'outsider' nor 'insider' to the organisation where the research was to be conducted. Although officially not a paid member of staff and having no managerial responsibilities, I had held a position within the organisation as the academic link lecturer. I had worked clinically at Site 2 and was well known by staff across the Trust.

4.6.1 Step 1: Sample

A convenience sample was used for the participatory observation phase. This sample included all the staff working in, and all patients and their family/friends attending, the outpatient and CDUs of the research site during the time of the data collection. Healthcare professionals included: healthcare support workers, nurses (all levels), pharmacists, doctors and other allied healthcare professionals (AHPs), for example, dieticians.

4.6.2 Step 1: Preparation for Fieldwork

Participatory observation in qualitative ethnographic fieldwork is often described as 'unstructured observation'. However, this does not infer that it is conducted in a haphazard or disordered fashion (Mulhall, 2003). The process was conducted rigorously. Preconceived judgements and conclusions about the setting and people who were being observed were avoided (Green and Thorogood, 2009). As Fetterman (2010, p.1) states, '*the ethnographer enters the field with an open mind not an empty head'.*

A number of challenges were encountered which needed to be addressed before data collection could start (June 2011). These concerned gaining access to enter the field and organising what, when and how to observe while participating in the work of the unit, in other words the practicalities of doing the observation. Mack et al. (2005), Robson (2011) and Green and Thorogood (2009) recommend a number of steps that need to be considered to help prepare the researcher and participants before observation begins, these include:

- Determine the purpose of the observation in relation to the research objectives.
- Determine who will be observed.
- Access the field, gatekeepers and informants.
- Determine when and for how long the observation will periods occur.
- Consider your role and how you present yourself including appearance, attitude and purpose.
- Plan how to undertake the observation – how to do it, what to observe and how to participate.
- Plan how to write notes during the participatory observation.
- Plan how to write up field notes and expand notes taken in the field (preferably within 24 hours).

Guided by the Lead Cancer Nurse (who was the study's clinical site lead), key gatekeepers were identified and approached, including members of the Trust and cancer directorate's leadership team, requesting permission to do the research. In these meetings an explanation of the study was given. Guidance and information was also received, for example, names of other key informants and events or situations that might be useful to attend. They also offered, usually unsolicited, their valuable and interesting perspectives about the aims of the study.

Formal meetings were held with the unit's nursing staff. In these meetings the background and rationale for the study was presented. All the staff were interested, asked lots of questions and offered ideas, and appeared willing to be involved. At these meetings staff were also asked what they thought about research and whether they had previous experience of being involved in a study. Most admitted they thought research involved '*a lot of hard work'* and very few had experience or undertaken research themselves. After these formal meetings some nursing staff and one doctor individually expressed concerns about the impact of the research on the units and whether they were '*too busy'* to help. I stressed the importance of informing me if this were to be the case and most were reassured by this. These introductory visits helped build relationships. Most staff began to see me in a different role and useful insights were gained into the organisation of the two units (Okumus et al, 2007). While preparing for the role I attended Trust mandatory study days, which included sessions on fire, health and safety, safeguarding adults and moving and handling in clinical practice.

When starting the observations it soon became apparent that organising what was actually going to be observed would be a challenge and at the time felt overwhelming. As Robson (2011, p. 324) states *'the immersion process of actually getting 'into' the group can be both confusing and stressful. Have faith – what may seem to be total chaos will, with time, reveal pattern, structure and regularity'*.

4.6.3 Step 1: Organising the fieldwork

There is little guidance in the literature on the practicalities of organising how you should approach doing the observations (Mulhall, 2003). Robson (2011, p 326) draws comparisons between the role of the researcher and that of the investigative journalist, both of whom are trying to get a thorough understanding of 'the whole story', a true description of the event or people involved.

A simple technique, which is taught to all novice journalists (and to me as child by my father, a journalist) was used initially to help organise the observations. It is described as the '5 W's and H' technique. The title came from Rudyard Kipling's (1902) poem, Six Honest Service Men. This very simple method provides a framework based on: what, why, when, where, who and how, type of open questions. The idea is that if all these questions are answered, journalists would obtain the 'full story' even in the most complex reporting assignments (Gibbs and Warhover, 2002). Stringer (2007) and Van de Ven (2007) have advocated that researchers use simple strategies, such as this technique, to help identify and formulate social research problems. However, it is acknowledged that what separates researchers from investigative reporters is that in social research the 'story' is not merely a valid description but a much deeper, theoretical understanding of the culture or groups being studied (Green and Thorogood, 2009). Examples of the questions can be seen in Table 8 below (for a more comprehensive list see Appendix 5).

Table 8: The 5 W's and H' Technique

	Examples of Specific Questions
Who	**Events or specific situations: Who is it about?** • Who attends with the patient are they their carers?
What	**Events or specific situations: What happened?** • What events have happened that have caused the patient or carer to contact the unit?

	Examples of Specific Questions
Where	**Events or specific situations: Where did it take place?** - Where do healthcare professionals interact with carers?
When	**Events or specific situations: When did it take place?** - When do carers attend with patients?
Why	**Events or specific situations: Why did it happen?** - Why do carers attend with the patient?
How	**Events or specific situations: How did it happen?** - How do healthcare professionals address and manage patient and carers concerns?

4.6.4 Step 1: The Observations

Participant observation started at both sites in September 2011 and continued until September 2012. Each site was visited on alternate weeks and observed for periods of four to six hours, up to two or three days per week. These visits occurred at Site 1 twenty-six times and twenty-three times at Site 2. Altogether over 250 hours of formal participant observation was conducted. There were breaks in the observation periods due to illness and holidays.

The observations started in the CDUs. However, during the fieldwork I spent a lot of time just 'being' around the units, in offices, staff rooms and going for lunch with the staff. While observing I had conversations, described by Fetterman (2010) as 'informal interviews', with patients and their visitors about their chemotherapy treatment experiences and with staff about their experiences of every day working life and interactions with patients and carers. These conversations '*help the fieldworker identify shared values in the community - values that inform behaviour'* (Fetterman, 2010 p. 41).

After a number of observations in the CDUs it became noticeable that a lot of practitioners' work with patients and carers was conducted 'behind closed doors', in consultation rooms. Different types of consultations were observed, including: consultations to consent for chemotherapy (doctor-led); the pre-chemotherapy consultation (also described as the 'work-up' or 'pre-chemo chat' led by nurses); and the on-treatment review (conducted mainly by doctors or in some cases nurse-led clinics). These reviews or chemotherapy toxicity assessments were conducted again by CDU nurses immediately before each cycle of treatment was administered.

Four clinical nurse specialists (CNSs) were shadowed throughout their working day. CNSs are frequently described as the patients' keyworker, whose role is to provide a vital link between patients and their families and the hospital (NICE, 2004). Therefore, CNSs were likely to be a primary source of support for carers during the treatment period.

4.6.5 Step 1: Participation on the CDU

A challenging aspect was how I could meaningfully participate, within the scope of my professional practice and cause only minimum disruption to the work of practitioners. A criticism of participatory observation is that important data can be missed, because researchers become over involved in the work (Kawulich, 2005). However, participating in the units was considered the best way to conduct the observations, enabling access to different sources of information as they presented themselves. The CDU Sisters made a number of sensible suggestions (see below). As I continued to work in the setting, the staff became more confident to ask me to do things. This list grew and my participation within the unit increased.

- Patient observations (temperature, blood pressure, pulse).
- Make tea/coffee for patients, visitors and staff.
- Answer the phone
- Do simple administrative tasks (help the ward clerks)
- Welcome the patients and visitors to the unit and record their presence.
- Talk to patients and their visitors.
- Shadow a nurse for the one whole observation period (4 hours).

4.6.6 Step 1: Other Observations

As previously identified, consultations between healthcare professionals and patients/carers were observed. In these, my role was one of participant-as-observer. When appropriate, tasks included: ensuring patients were comfortable, helping patients get undressed if required, sorting out notes, tidying clinic rooms between appointments and making tea/coffee for staff. Questions included:

- Who attended with the patient?
- What was the appointment for?
- Which staff members were present?
- What was discussed?
- What information was asked for by the patient and the carer?
- Was the carer involved in discussions and if so by whom?
- How did the clinician involve the patient/carer in the consultation?
- Length of appointment
- What communication skills were used by the clinician?

Five multi-disciplinary team meetings were attended (MDM). The purpose of these mandatory MDMs is to plan and agree the patients' treatments in a multi-disciplinary forum. My role in these meetings was one of observer-as- participant. Questions included:

- How were these meetings organised?
- Were carers discussed – what, how, when and why?
- Were patients' psycho-social and supportive needs discussed – what, how, when and why?
- Who attended?
- Who contributed to the discussions?
- When do these meetings happen?

During the fieldwork period I also met with many healthcare professionals who were involved in some aspect of caring for cancer patients and their families, either at the treatment centres or in the community, for example, GPs and hospice.

4.6.7 Step 1: Recording Findings

While observing shorthand notes were recorded in a small notebook. The notebook was small enough to be kept in my tunic pocket, so could be discretely put out of view when required. These notes were typed up in full, as soon as possible after the observation period (usually within 24 hours). A personal reflexive research diary was maintained throughout the study. This was vital as it helped me to reflect and consider how my own values, preconceptions, behaviour or presence in the clinical setting, influenced the events I observed or heard (formal and informal interviews); and how I interpreted them (Pope and Mays, 2006).The diary was exceptionally useful as an 'aide memoire' during the analysis and interpretation of findings.

Information was documented using a simple audit tool. This was used to establish who came with the patients to their chemotherapy appointments; at which point carers came in the treatment phase; if there was a particular reason for the friend/family member to attend; what services carers were offered and used, and which healthcare professionals were involved or offered help to carers. Information was also collected from a clinical audit of telephone calls, received by Site 2's out of hour's service, over a period of one month (May 2012), identifying who sought advice (patient or carer) and for what purpose.

At the end of the data collection period there were more than five small notebooks of shorthand notes. Initially these notes, when typed into long-hand, were long descriptions that tried to capture everything that had been seen or heard. However, as the fieldwork progressed, these notes became more condensed and focused on main themes, patterns or questions that had emerged during the observations. As well as the field notes and reflexive diary, a 'decision audit trail' was kept. This was simply a list, recording key decisions and reflections made throughout the study. Information included: key meetings and communication with stakeholders, a brief rationale for any methodological changes to the research process, reflections and questions about the data and interim interpretations of findings.

4.6.8 Step 1: Informed Consent

A study pack including a written invitation, study information and consent forms was given to all staff working in the clinical area before data collection commenced. As already highlighted, formal group and individual meetings were held with all the healthcare professionals working at both sites at the start of the study. At these meetings they were able to receive more information about the research objectives, ask questions and raise any concerns. However consent was repeatedly sought and sometimes renegotiated with participants throughout the fieldwork.

Due to the nature of outpatient chemotherapy work, it was difficult to ensure that patients and visitors had time to think about participating in the study before they came to the department for treatment. For the ethics committee, who reviewed my application to the Integrated Research Application System (IRAS), this issue was contentious; as it is preferable to give people at least 24 hours to think about participating in research, before providing informed consent (Moore and Savage, 2002). To address their concerns, the following was agreed:

1. Posters providing information about the study and reassurance that participation is entirely voluntary were placed around the chemotherapy day units (Appendix 6).

2. Patients were sent a letter at least one week before their booked appointment; this informed patients that research was being conducted in the department while they were having their treatments.

3. All patients present in the units would provide written informed consent. When patients attended their appointments, they were provided with a study information sheet and asked to sign a consent form.

However, after six weeks observing in the CDUs it became evident that sending letters and the process of obtaining written consent, from all patients and visitors that attended the clinic, was proving unhelpful and disruptive to the unit environment. It also impacted on the methodological rigour of the research. More time was being spent gaining patients' consent rather than actually observing what was going in the clinic. Patients and their visitors acknowledged to the staff and me that they were finding the process of providing written consent over-burdensome and intrusive. The letters sent to patients also seemed to raise patients' and their families' expectations. Staff noticed more people attended with patients at the CDU than usual and most of these visitors had anticipated that I would spend time talking to them. None of us were happy with this situation.

In November 2011, two months after the participatory observation period began a substantial amendment was submitted to the ethics committee. This amendment sought permission to stop sending letters to patients prior before their appointments and to obtain verbal rather than written consent. The ethics committee responded quickly and agreed to the amendment (dated December 5, 2011).

Patients and their visitors were, therefore, provided with information about the study usually as they arrived at the reception desk. This gave them time to read the information in the waiting room. When they entered the unit patients and visitors were asked to provide verbal consent on each observation period. This request was always made in the presence of a member of staff. Where patients were not able to give consent (communication difficulties), their carer or family member was asked (Mulhall, 2003). No patient or visitor objected to being observed. Indeed, nearly all were extremely willing to share their stories, even before they had read the information sheets.

4.7 Step 2: Formal Interviews with Carers

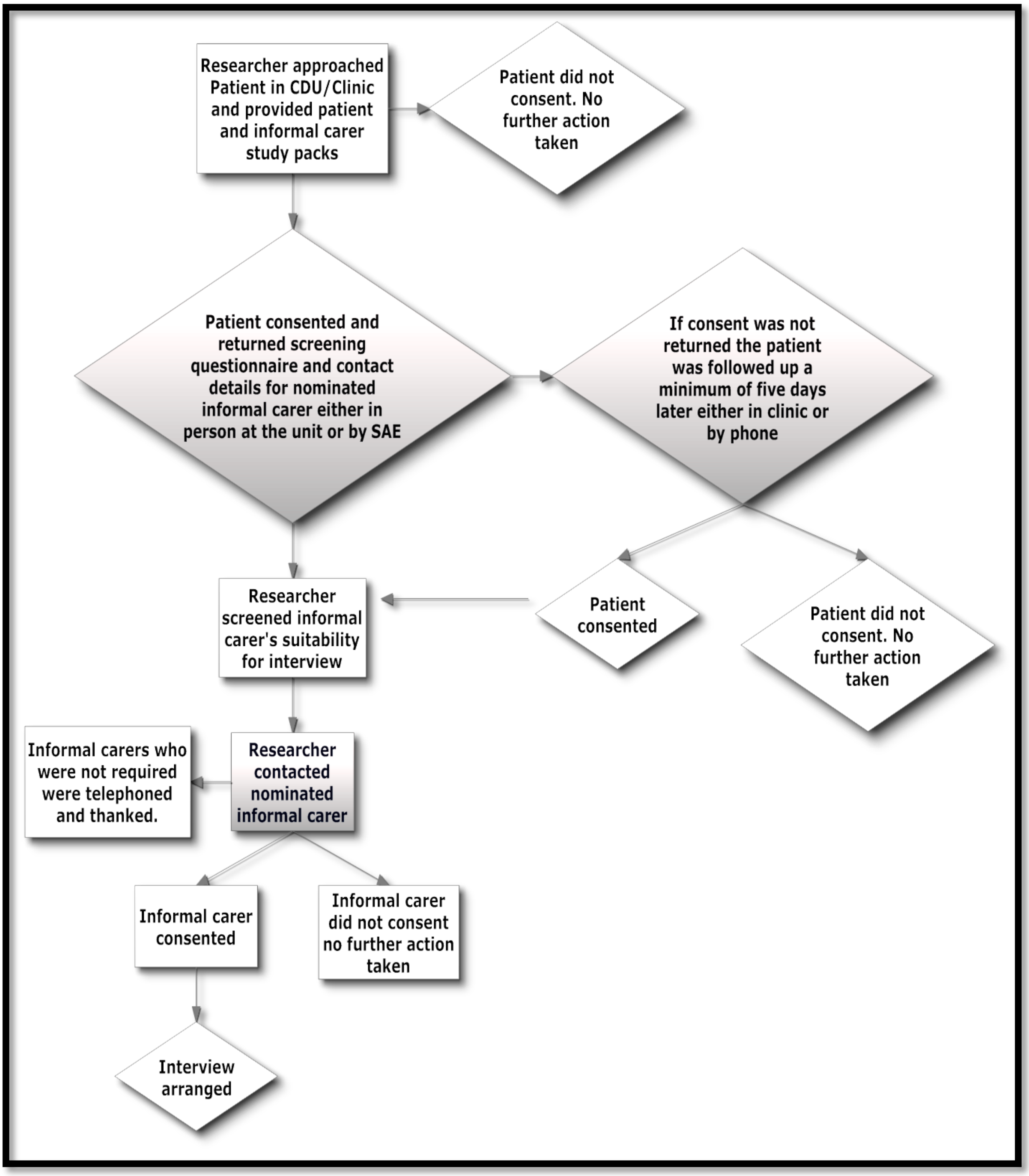
During the period of participant observation, the process of identifying and recruiting carers for formal interview began. The aim of these interviews was to explore carers' perceived needs for preparation, support and information when caring for the patient receiving chemotherapy. Ethics approval was granted for interviewing up-to 25 carers.

A semi-structured interview schedule (Appendix 7) was developed from the literature and previous work undertaken in this area (Ream, 2010) and with guidance from members of the carer advisory group. Themes explored included carers' experiences of supporting patients receiving chemotherapy, their perceived needs, needs that were addressed well and those that were not, how unmet needs could have been addressed and specific points in the treatment trajectory when need for support and information were high. Other themes explored included: communication with healthcare professionals; barriers to accessing care; events that have made them feel anxious or created insecurity at home; triggers for seeking professional help, and whom they received help from, and interventions they thought might help.

4.7.1 Step 2: Identification and Recruitment of Carers

Initial access to the carers was made through the patient (Figure 7 below). The CDU nursing staff helped to identify all eligible patients who met the inclusion/exclusion criteria. These patients, who had previously consented to the participatory observation phase of the study, were approached, provided with a full explanation and asked if they would be willing to consider participating in this next step by allowing their carer to be interviewed.

Figure 7: Recruitment Process for Carer Interviews



CDU = Chemotherapy Day Unit

To help patients decide who they should nominate as their carer, they were asked "who supports you the most while having chemotherapy?" Further guidance, adapted from Thomas et al (2001), was provided on the information sheet to help patients identify who they should nominate, as follows:

- This person is the person who comes immediately to mind as most involved in supporting you through chemotherapy treatment. This person is often a husband, wife, or partner but sometimes a relative or friend.
- This person can be a man or woman of any age, who may or may not live with you.
- This person may not necessarily do physical tasks for you, such as cooking or cleaning but they may provide, for example, company and emotional support.
- This person is **NOT** someone who is paid to look after you (e.g. a nurse or home help).

Patients received two study information packs, one for them and one for the person they nominated as their carer. Patients were asked to give their nominated person the ‘carers study pack’. These packs contained an invitation letter, study information and a consent form (Appendices 8, 9, 10). Screening questions were also included in the patient pack to help obtain a purposive sample with variability, with regards to gender, ethnicity, and type of chemotherapy, side-effects and relationship to patient (Appendix 11). The patient was asked to provide written consent and contact details, so that their nominated carers could be approached either in person or by telephone.

The patients and carers were given a minimum of five days to consider whether they wanted to participate or not. If the carers did not respond, patients were approached when they were next in clinic and were gently reminded about the study and asked if they and the carer wished to take part in the study.

Those carers, who sent back the reply form indicating willingness to be considered for interview were either approached in the clinic or telephoned to explain the process and confirm their willingness to participate and arrange a time and venue suitable for undertaking the interview.

Written informed consent was obtained from carers, prior to interview. In addition, participants had the opportunity to ask questions during the initial contact telephone call and immediately preceding the interview.

4.8 Step 3: Formal Interviews with Patients

At the beginning of the study, I had decided not to interview patients, choosing to focus on carers and healthcare professionals. I was concerned that interviewing patients about their families and friends may cause them undue distress. It was also envisaged that informal conversations with patients during observations would provide enough data about their feelings towards the study aims (Allan, 2010). However, it became apparent that formally interviewing patients might clarify some issues that had arisen in both the observations and carer/health professional interviews. Guidance was sought from the project and carer advisory groups; carer advisors suggested excluding patients, was comparable to a "*stool with two legs*". Members of both groups thought that patients would offer valuable and different perspectives which could inform the findings. The patient and carer advisors provided reassurance and guidance for managing the sensitive nature of the interviews. They also reviewed the interview schedule and made suggestions about the questions and conduct of the interview. A substantial amendment was submitted to the ethics committee to request permission to interview up to ten patients. This amendment was granted on July 17, 2012.

A semi-structured interview schedule provided guidance during the interviews, (see Appendix 12). Themes explored included the patient's understanding of the role of the carer, their perceptions of carers' needs and how unmet needs may be addressed as well as specific points in the treatment trajectory when need for support and information were high. Other themes explored included: communication with healthcare professionals and carers; their perceptions of barriers to accessing care; events that have made them feel anxious or created insecurity at home and how the carer supported them; triggers for seeking professional help and whom they and their carer received help from.

4.9 Inclusion/Exclusion Criteria for Steps 2 & 3

4.9.1 Criteria for Patients:

Inclusion

Eligible patients were:

- Adults over 18 years of age.
- Able to understand and write English.
- Had a cancer diagnosis.
- Nearing completion of their first ever course of chemotherapy treatment.
- Willing for their carer to be approached.

Exclusion

Patients were excluded if they:

- Were receiving second or subsequent courses of chemotherapy.
- Had a degenerative illness or other condition affecting cognition and/or comprehension.
- Had a life expectancy of less than six months.

4.9.2 Criteria for Carers:

Inclusion

Eligible carers were:

- Adults over 18 years of age.
- Nominated by patient as someone who provided most of the support to the patient receiving chemotherapy.
- Someone who was supporting a patient who had received chemotherapy treatment for the first time.
- Able to understand and write English.

Exclusion

Carers were excluded if:

- They had a degenerative illness or other condition affecting cognition and/or comprehension.
- They were unable to cope, physically or emotionally, with the research protocol.
- They provided support for a patient who is receiving second or subsequent courses of chemotherapy.
- They cared for a patient who was considered to have a life expectancy of less than six months.
- They were carers but did not have permission from the patient to be included.

Patients who had a life expectancy of less than six months and receiving chemotherapy for symptom support were excluded. Carers who were also caring for patients with a life expectancy of less than six months were excluded. These carers may have many needs but these were more likely to be around caring for someone who was dying rather than supporting someone through chemotherapy treatments in the acute/active treatment setting.

4.10 Step 4: Formal Interviews with Healthcare professionals

The overall objective of this step was to identify healthcare professionals' perceptions of carers' needs, what they perceived they were and how they should be addressed and their perceptions of barriers to carers being adequately prepared for their role. Ethics approval was granted for interviewing up-to 25 members of staff. These included medical staff, nurses, clinical managers, support workers and associated health care professionals.

A semi-structured interview schedule was used to guide interviews (Appendix 13). Themes explored included: healthcare professionals' understanding of the role and needs of carers when supporting patients at home; the support given to carers in the acute and primary care settings;

the perceived barriers (organisational, clinical, knowledge deficits and emotional aspects) preventing staff from providing support and how these could be overcome.

4.11 Interview Conduct

The interviews with carers, patients and healthcare professionals were all conducted in person or by telephone and were digitally recorded and transcribed. Participants were given the choice of venue; for carers and patients this could be either at home or in the hospital and for healthcare professionals at their workplace or other venue of their choice. All participants received a study information pack, which contained an invitation letter, study information and a consent form. Written informed consent was, therefore, obtained from all the participants.

The interviews were conducted in a six stage approach advocated by Legard et al (2003). Essentially within each of these stages the researcher plays the role of a 'stage-manager' who sensitively guides the process to enable participants to talk openly about their thoughts, feelings and experiences. During the interviews a particular strategy was used, described as '*mapping and mining'*. This technique makes use of cues, prompts and probing questions to help direct the participant, aiming to gather more detailed data (Legard et al, 2003). Open questions were predominately used. Closed questions and technical jargon were avoided where possible, to prevent participants 'closing down' (NatCen, 2011). The participants had control over what they chose to disclose and also the environment in which interviews were conducted.

4.12 Step 5: Fieldwork Analysis

The analytical processes commenced at the beginning of the fieldwork and subsequently iteratively informed both the research design and interpretation of findings (Lathlean, 2010).The fieldwork generated huge amounts of data and paperwork. To help make sense of the data, a number of steps within the analysis process were performed. These will be described individually, but included:

- Field notes: Thematic analysis
- Key decision trail
- Reflexive diary
- Interviews: Framework analysis
- Story boards
- Writing the results chapters

4.12.1 Analysis of Observation Field Notes

The analysis of observation data started immediately the fieldwork began, as it was impossible not to begin thinking about what had been seen. Although an inductive approach was taken, interpretations were shaped by the questions related to the aim and objectives of the study.

During the initial, tentative analytical processes, the data was explored and reflected upon during informal meetings with participants at the research site and with members from both of the project advisory groups.

The observations generated a vast amount of notes. To manage the data, a simple thematic analysis process was used. This process was iterative and evolved during the observation phase. Braun and Clarke (2006, p.9) suggest thematic analysis is used *'both to reflect reality, and to unpick or unravel the surface of reality'.* Initially, the observation field notes were read and re-read. While doing so further areas, which needed to be explored during both observation and interviews, were identified (Allen, 2010). Initial codes were generated and key themes became apparent (see Appendix 14). The notes continued to be read and re-read in chronological order, in order to refine the themes (Braun and Clarke, 2006; Allan, 2010).

As previously described, an audit decision trail was logged. This was simply a chronological list of dates when key observations and meetings occurred or reflections and decisions were made that influenced for example, the observation or interviews and the overall design of the research.

4.12.2 Data Analysis of Formal Interviews

The interviewing of healthcare professionals and carers ceased when a lack of new emerging data and insights suggested that data saturation had been reached (Kawulich, 2005). Framework analysis was used. This method is particularly useful for managing large quantities of generated data (Pope and Mays, 2006). Previously used as a method for analysis in the review of reviews (Chapter 2). However, for the interview data a computer assisted qualitative data management package NVIVO, version 10 was used (Ritchie et al, 2003). The steps undertaken are as follows:

1. **Familiarisation with the data**: the tape recordings were listened to, at the same time the transcribed interviews were read and notes were made in the margins.

2. **Developing a thematic framework or index**: this involved reading through a number of interviews and developing a long list of what appeared to be important themes or concepts. These lists evolved during the next step to become the analytical framework for carer (Appendix 15) health professional (Appendix 16) and patient interviews (Appendix 17).

3. **Indexing and coding of the data**: this involved reading and re-reading the interviews, and creating order to the themes previously identified, making a list of codes under each of the themes. Each interview was read through and data was indexed under the different codes. This process is iterative, having completed the first coding process the interviews were checked again

to ensure all the relevant themes and codes had been identified. Codes were added if they had been missed previously.

4. Once all the data from each of the individual interviews had been indexed and coded, the next step was to **chart the data,** in a matrix format. This was usually verbatim text although sometimes the text would be summarised. Using NIVO enabled the summarised text to be linked to the quotes within the transcribed interviews.

5. The fifth step involves **mapping and interpretation of the data**; patterns within the data were then explored and compared (Ritchie et al, 2003). This process was guided by the research aims and objectives as well as themes that emerged from the data (Pope and Mays, 2006).

4.12.3 Analysis to Synthesis: Fieldwork Findings

The generated data, towards the end of the fieldwork, had started to become overwhelming. To help make sense of the data, 'story-boards' were developed. These were simply eleven A2 sized cardboard sheets. These contained images obtained from Google Images to illustrate some of the main findings and quotes from both informal and formal interviews. These 'story boards' also became a useful tool for sharing some of the findings with supervisors, advisors and participants (for examples see Appendix 18).

However, comprehensive synthesis of the findings did not begin properly until I started to write the results chapters. During this writing process I moved back and forth between all the analysed data and frameworks, drawing out key themes for discussion. The matrix charts of the findings from the interviews and review of reviews made this process more visible and it was easier to explore similar themes and emerging patterns. I was careful to ensure the 'stories being told' were the perceptions and voices of the participants. The findings from the observations and interviews were synthesised and presented together in Chapters 5 and 6.

4.13 The Modelling Phase

4.13.1 Writing about Methods

The modelling phase was underpinned by the principles and practices of action research. Reporting the methods and findings pose a particular challenge for action researchers. This is because they are interconnected. The actions create the findings, which in turn influence the actions. Hence it is difficult to separate the two (Williamson et al, 2012; Springer, 2007). Therefore, reporting the process in a manner which is meaningful and logical requires some flexibility and creativity (Koshy et al, 2011). The participatory meetings, how they were conducted, the techniques used and the subsequent actions and activities of the modelling phase will be discussed in-depth in Chapter 7.

4.13.2 Modelling Phase: Ethical Considerations

One of the main ethical challenges of action research is making sure participants are able to provide genuine informed consent (Meyer, 1993a). Action research methods have a high risk of participant coercion, resulting in participants feeling unable to withdraw from the study. Importantly, due to the nature of action research it was challenging to outline at the beginning of the project what may happen for example, what the intervention or the proposed changes would be. Asking people to become participants in these circumstances was essentially asking them, especially the healthcare professionals, to 'step into the unknown'. Meyer (1993a, p. 1069) suggests consent in action research, '*really centres around the participants willingness to take part in the project ideas and acceptance of the researcher as facilitator of change'*. In this study informed consent was sought from participants in stages (Froggatt et al, 2013). Participants could choose to opt in or out at different points. The aim was to ensure that participants would be able to make a more informed decision of whether they wanted to be involved in each phase of this research.

At the end of the pre-clinical phase many rapid changes were occurring at the research site. The Trust was about to go through yet another re-organisation. The hospital sites (site 1 and 2) were to be split and remerged with other Trusts. I had profound concerns and questioned whether continuing with the modelling phase of the study was tenable. This phase was going to involve introducing change at a time when the workforce was already going through significant restructuring. To continue might have been detrimental to both the participants and to the research.

Advice was sought in August 2012 from senior healthcare professionals, members of the advisory group who were aware of the current situation of the Trust, about whether the research should continue. They also had some misgivings, but I was strongly advised to act quickly and ask the staff at the Trust, before making a decision to stop the research. When asked, the healthcare professionals at both sites insisted that they had come this far, '*it is only fair that we continue'* and they wanted to try out new ways of working. Indeed, one member of the team pointed out that this project had been the *'only really positive thing when a lot of bad things were happening'.*

Although the workshops were covered by ethical permissions, the modelling phase of the study was not. Guidance was sought from the REC and Trust R&D administration personnel about whether another IRAS application needed to be submitted. In response they deemed the next phase to be 'service development' and as it focused on staff a further application was not required. They did, however, extend the time-frame of the original application.

4.14 Strategies to Enhance Rigour and Ensure Quality

In the previous chapter (section 3.12) a number of strategies recommended for establishing quality in qualitative and action research were outlined. Lincoln and Guba’s (1985) criteria for assessing qualitative research, predominately guided the initial pre-clinical phase of this study. While continuing to draw upon these criteria, Waterman et al’s (2001) list of recommended questions used to assess the quality of action research projects primarily guided the action research phase of this study.

4.15 Chapter Summary

This chapter has provided an account of why and how the methods were employed to meet the overall aim and objectives of this study. An overview of the data collection, participatory and analysis methods used in both phases can be found in Table 9 below.

Table 9: Overview of Methods

Phase	**Time Frame**	**Data Collection Methods**	**Data Analysis**	**Levels of Engagement/Participation** Experts and Intended Beneficiaries/End Users of the Intervention
Phase 0 (Pre-clinical)	Jan 2011 – Jan 2012 and updated Nov 2013	• Systematic Review of Reviews: Carers in the chemotherapy setting	• Framework Analysis	• **Consultation** • Findings reported to advisory groups
Needs Assessment /Problem Formulation: meeting the first 4 objectives	September 2011- September 2012 Feb 2012 – Sept 2012	**Fieldwork** • Participatory Observation (+250 hours) • Formal Interviews ○ Healthcare professionals (n=22) ○ Carers (n=13) ○ Patients (n=3)	• Thematic Analysis • Framework Analysis	• **Consultation** • Formal/informal meetings with: ➢ Trust/ Research Site Doctors and Nurses ➢ General Practitioners and District Nurses ➢ Service improvement leads ➢ Cancer Network Leads ➢ Carers advisory group ➢ Carer groups (From local area to research site, including a hospice group) ➢ Project advisory group
Phase I (Modelling) Theory Building/ Problem Solving	November 2012	• Workshops (n=2)	• Thematic Analysis	• **Collaborative, high level of engagement and participation** ○ Site 1 x 12 participants ○ Site 2 x 9 participants
	February 2013	▪ Expert consensus meeting (modified- nominal group technique) ○ Identifying the key components of the pre-	▪ Thematic	• **Collaborative, high level of engagement and participation**

Phase	Time Frame	Data Collection Methods	Data Analysis	Levels of Engagement/Participation Experts and Intended Beneficiaries/End Users of the Intervention
		chemotherapy consultation ○ Developing a DVD of consultation skills.		○ Experts – key stakeholders and participants
Phase 0 **(Pre-clinical)** Theory Building	Sept 2012 onwards	• Consultation and communication skills – explored in the literature (discussed in chapter 8) • Visits to other Trusts (described in chapter 7) • Attended different communication skills training including: SAGE & THYME Training • Met with people from other healthcare backgrounds who had developed training to help practitioners become more ‘carer aware’ (described chapter 7)		• **Consultation** ○ Consulted with communication skills experts/colleagues ○ Findings shared with carers and stakeholder/project advisory groups. ○ Findings shared and explored with practitioners in participatory meetings
Phase I **(Modelling)** Develop model to study theory	Started from Nov 2012	• Formal and Informal Meetings • Email correspondence ○ Development of two tools to promote engagement between healthcare professionals/carers: ▪ The Support Notebook ▪ The fridge-magnet	• Thematic	• **Participant led and collaborative, high level of engagement and participation** ○ Nurses from research sites ○ Carer Advisory Group ○ Project Advisors
	Started from April 2013	• Testing for acceptability ○ The Support Notebook ○ The fridge magnet	• Thematic	• **Participant led, mostly high level of engagement and participation** ○ Nurses from research sites
	June 13, 2013 July 11, 2013 Sept 19, 2013	• Evaluation of acceptability ○ Focus groups (n=3)	• Thematic	• **Collaborative, mostly high level of engagement and participation** ○ Nurses from research sites

Chapter 5 Fieldwork Findings: Carers

5.1 Introduction

To meet the objectives of the pre-clinical phase fieldwork data collection methods consisted of more than 250 hours of participatory observation, basic audits and in-depth interviews with healthcare professionals (n=22), carers (n=13) and patients (n=3). What transpired over the data collection period is what Smith (1992, p. 135) describes as a '*voyage of discovery*'. The process was iterative; each step of the fieldwork uncovered more questions and areas to explore. Observation findings informed the design of interview schedules. Issues that arose in interviews were subsequently explored through observation. However, it was often impromptu conversations with patients or healthcare professionals that significantly impacted and elicited new conceptual discoveries. Indeed it should be noted that uncountable informal interviews or conversations occurred with patients, visitors and staff throughout the observation period. Quotes from the informal interviews are used in the following chapters to represent or illustrate many of the findings obtained through conversations in the fieldwork.

In this chapter, the fieldwork findings reporting the perspectives of carers, patients and healthcare professionals, from both observations and interviews, are presented. The clinical settings and how the work is organised will be described. However, the main focus of this chapter is the carers. Their roles and challenges are described. Also outlined are carers' needs for role preparation, information and support and how these are currently met by practitioners.

5.2 Background to Research Site

The research site for this study was a large hospital which had been created from a merger of three smaller general hospitals, Sites 1, 2 and 3; to create a single NHS Trust. The distance between Site 1 and Site 2 is sixteen miles with Site 3 situated halfway between the two.

At the beginning of the study, the Trust's cancer services had recently undergone significant change because of the merger. All the cancer services at Site 3, except for the Macmillan Information Centre, were closed. Patients and staff were greatly affected by this change. Patients living near to Site 3 now had to travel to the other sites. The number of patients being treated at these two sites increased, impacting on workload capacity and space.

Employees from Site 3 were re-deployed to positions on the other sites or were offered different positions in other non-cancer services at Site 3. However, during the data collection period Site 3 was re-opened and a nurse-led service was provided for cancer treatment support. Patients requiring treatments such as blood transfusions or hormone therapies were sent to Site 3; while the other two sites focused on providing systemic chemotherapy treatments.

Due to the Trust's financial difficulties, services and resources had been streamlined and in some cases cut. Nursing roles at every level had been scrutinised. Clinical nurse specialists (CNSs) for example, had experienced three job consultations since the merger. Staff repeatedly told me that *'people will lose their jobs'.*

During the study, nursing team numbers were reduced. Nurses left the Trust for many different reasons including ill-health, retirement and new career opportunities. These nurses were not replaced. The breast cancer team at Site 2, for example, consisted of five CNSs at the beginning of this study one year later the service had only one CNS. There had also been significant changes to the Trust's management teams described in an informal meeting in June 2012 by one of the Trust's senior nurses as now 'running very lean at the top'. The lead cancer nurse responsible for overseeing the cancer service within the Trust left in April 2012. This post was covered in the interim by a matron from Site 2 who then managed all nurses in the Trust's cancer service. This person also took on the role of clinical lead for this project.

While undertaking the fieldwork the Trust's financial problems were noticeable and basic resources were often difficult to obtain, for example printers did not work. Staff shortages were also a problem and there was constant movement of nurses between sites, wards and units to '*plug the gaps'* (comments by Senior Nurses). Unless there was a significant crisis no agency staff could be employed. These problems were a constant source of frustration and anxiety for the staff.

In the field notes conversations with healthcare professionals were recorded daily about their anxieties regarding the organisational changes occurring at the Trust. The upheavals left staff always feeling uncertain about the future, described by one participant as *'constantly running on shifting sands'* (Senior Nurse).

5.3 Fieldwork Participants

Due to the nature of work undertaken in an outpatient setting it is difficult to give an exact number of those involved in participatory observation. All staff who worked at the cancer unit (inpatient and outpatient settings) were provided with information regarding the study either in meetings or via email. All permanent staff who regularly worked in or entered the CDU (both sites) provided written consent (Table 10).

Table 10: Fieldwork Participants: Staff

Site 1	**Site 2**	**Staff who Worked across Site**
Qualified Nurses (n=10) Support Workers (n=1) Doctors (n=3) CNS (n=4) Pharmacist (n=1) Dietician (n=1)	Qualified Nurses (n=9) Support Workers (n=2) CNSs (n=10) Doctors (n=4) Pharmacist (n=1)	Senior Nurse Managers (n=4)

Seven consultant led clinics were observed. These included three doctors at Site 1 and four on Site 2. All of whom provided written informed consent. Four senior nurse managers who worked across the Trust sites also provided written consent. On an average day there were as many as 25 patients being treated in each of the CDUs. During a four-hour observation period in the CDU, there could be up-to eight patients receiving chemotherapy.

5.4 Description of the Trust's Cancer Service Units

The study took place on two of the Trust's sites, Site 1 and Site 2. These two sites contained two cancer units (Site 1/Unit 1 & Site 2/Unit 2). These were both similar in layout, size and function. Both were self-contained and felt separated from the main hospital sites. Each consisted of an outpatient department with a large waiting area and clinic/consultation rooms. Branching off from here were the chemotherapy day units (CDU), an inpatient ward and offices utilised by cancer service administration staff and senior nurses and medical staff. They also had a similar 'feel'; both units were clean and light but, the furniture was due for updating.

Both sites were operating at full capacity. Many CNSs stated that they had more than 150 patients as a current patient case-load. The CDU managers told me the number of patients being treated in the units had increased by 40 per cent since the previous year.

The demographics of the patients the sites served were very different. Site 1 provided cancer care for a very ethnically diverse population; the area also had high poverty and unemployment rates. At the start of fieldwork it became impossible to travel to Site 1 because of the September 2011 riots. Site 2 served a mostly affluent, less ethnically diverse and generally more elderly population.

5.5 The Chemotherapy Day Units (CDU)

5.5.1 Site One

The CDU at Site 1 consisted of a large room. At the entrance there was a long work station with computers and telephones. Here the support worker sat and would welcome patients and visitors to the unit. The CDU nurses also used this work station to conduct administration work and used the computers to check patients' treatment schedules, blood test results etc. Situated opposite this desk was a small clinic room where treatments were prepared. This room was often used by staff for coffee breaks or for private conversations. The main CDU room contained eight treatment chairs and one bed. The treatment chairs were placed on the circumference of the room, facing inwards. The CDU also used two beds on the in-patient ward for treating patients. Space was cramped between each of the chairs and visitors often positioned themselves opposite the patient's chair. The unit opened between 8.30 am until 6pm; frequently however, the patients' treatments would be delayed and the unit stayed open later than 6pm.

Treatment was administered to breast, lung, haematology, prostate and lower and upper gastro-intestinal (GI) cancer patients. The CDU was manned by four members of nursing staff three days a week and three nurses two days a week. Most of the nursing staff on this site had worked at the Trust for more than five years. On Mondays the CDU held a nurse-led clinic to review colorectal patients. This clinic was run in tandem with the medical oncology consultants' clinic. A Band 3 support worker provided administration support five days a week.

5.5.2 Site Two

The CDU at Site 2 was an unusually shaped room almost a hexagon; the work station desk was in the middle opposite the entrance. Behind the desk was a small clinic room also used for treatment preparation and discussions between staff. The main room contained six treatment chairs and unlike Site 1, this CDU had two further clinical rooms attached to it. One contained a bed and the other contained three further treatment chairs and scalp-cooling machines. These two rooms were used for the pre-chemotherapy consultations with patients and their support person. Space was extremely cramped in this unit with little room to move around the patients' chairs. For this reason patients were advised that they could only bring one visitor with them while having treatment.

Filing cabinets, containing patient notes were also in the main room. Staff who did not work in the CDU frequently came into the unit to find patient notes. One participant viewed this as detrimental to the work and environment:

> *'I just think it's like Waterloo Station and I really do not like that personally. But I feel as though I can't do anything about it. They're pushing past sometimes and they do not*

> *obviously know what I've got in my tray and what I've got in my trolley and I'm next to this patient. I find it really frustrating. I'm normally quite a calm person but I do find it frustrating because it's so dangerous'* (CDU Nurse S2:5).

The unit was usually manned each day by three qualified nursing staff and one support worker. The staffing levels at this unit fluctuated. For the majority of the research period staff from other clinical areas or the Trust's bank staff were employed; ensuring that there was enough staff to administer treatments. At the beginning of the study the CDU Sister left and was replaced by a new manager some three months later. Treatments were administered to breast, lung, haematology and colorectal cancer patients.

5.6 The Carer Interviews

Ethics approval was granted for interviewing up to 25 carers. However, just 14 carers were interviewed. This was because a lack of new emerging data and insights suggested data saturation had been reached (Kawulich, 2005). The interviews were conducted between March and September 2012. All were audio recorded except one (CB1a), for this interview in-depth field notes were written. Of the fourteen interviews, only thirteen were included for analysis. During one interview with a patient's husband, it became apparent that he did not meet the inclusion criteria; his wife was having chemotherapy for the second time. Both the patient and participant had been given full study information prior to interview. However, both had been extremely eager to be involved in the study, he wanted to tell me their '*story*'. I felt obliged to continue with the interview, but excluded the findings.

During observations, many patients volunteered their family or friends to be interviewed. The patients would state that *'this affects them more than me and they need to talk to someone'.* All the approached patients identified members of their immediate family, spouses and adult daughters as their main support person. One patient nominated his brother. Two patients (PB1 and PB2) when approached, told me that they were predominately supported by two people, their husband or partner and their adult daughter. Both sets of people were interviewed (CB1a & CB1b; CB2a & CB2b).

The interviews were conducted either at the patients and/or carers' home, over the phone or at the clinical site. The interviews lasted between 28 and 74 minutes (mean = 46). All the carers became emotional, some cried discussing their experiences. They often focused on the patients' experiences and needs rather than their own.

Five carers had been approached while attending the clinic with the patient. Although they were happy to talk in the clinic and were given information about the interviews, they did not consent. Reasons included they needed to concentrate on the patient, treatment was about the patient not them, and one had language difficulties and did not want to be recorded. A number of patients from Black and ethnic minority groups (BME, mostly Asian and Black African) were approached. Black African patients (mostly women) often came alone or with a female companion to clinic appointments. They were given information about the study but even with prompting none of the consent forms were returned. One Asian lady admitted that she had told only her husband of her diagnosis. While her family and friends were aware she was ill, none knew she had a colorectal cancer diagnosis. It was something she was ashamed of and she was unwilling to participate in the study.

Table 11: The Characteristics of the Interviewed Carer Participants

Carer Code	Site	Gender	Relationship with Patient	Lives with Patient	Age Range	Employment	Ethnicity	How/Where Interview was Conducted
CB1a	2	Male	Husband	Yes	50-59	Working full-time	White British	At home
CB1b	2	Female	Daughter	No	30-39	Working part-time: Child-minder	White British	At patient's home
CB2a	2	Male	Partner	Yes	40-49	Working full-time: Consultant Engineer	White British	At hospital
CB2b	2	Female	Daughter	Yes	22-29	Working full-time: Teacher	White British	By phone
CB3	2	Female	Daughter	No	50-59	Working full-time: Interior Designer	White British	By phone
CB4	2	Female	Wife	Yes	50-59	Retired	White British	At home
CW1	1	Male	Brother	No	Over 69	Retired	White British	By phone
CW6	1	Male	Husband	Yes	60-69	Retired	White British	By phone
CW7	1	Female	Wife	Yes	60-69	Retired	White British	At home
CW8	1	Female	Daughter	No	50-59	Not-working	White British	At hospital
CW9	1	Female	Wife	Yes	Over 69	Retired	White British	By phone
CW10	1	Female	Wife	Yes	50-59	Worked full-time but part-time during treatment: Hairdresser &Cleaner	European	At home
CW12	1	Female	Daughter	Yes	22-29	Working full-time:	Black British	By phone

Carer Code	Site	Gender	Relationship with Patient	Lives with Patient	Age Range	Employment	Ethnicity	How/Where Interview was Conducted
						Administrator at a Prison		

The table below describes the characteristics of the person the carer was supporting, disease and treatment they had received and occurrences of emergency hospital treatment for a chemotherapy related adverse event.

Table 12: The Characteristics of the Patients Whom the Carer Supported

Carer Code	Gender	Patient's Age	Patient's Diagnosis	Time since Diagnosis	Getting a Diagnosis	Phase in Treatment Trajectory	Type of Chemotherapy	Patient had Emergency Treatment	Type of Adverse Event
CB1a	Female	50-59	Breast	A year	No delays	Treatment on-going	Intravenous (IV)	No	N/A
CB1b	Female	50-59	Breast	A year	No delays	Treatment on-going	Intravenous	No	N/A
CB2a	Female	50-59	Breast	6 months	No delays	Coming to end of treatment	Intravenous	Yes	Infection
CB2b	Female	60-69	Breast	6 months	No delays	Coming to end of treatment	Intravenous	Yes	Infection
CB3	Female	Over 69	Haematological	Over a year	Not discussed	Treatment on-going	Both IV & Oral	Yes	Had more than one
CB4	Male	50-59	Haematological -	3-4 years	Delayed	Treatment on-	Both IV & Oral	Yes	Neutropenic

Carer Code	Gender	Patient’s Age	Patient’s Diagnosis	Time since Diagnosis	Getting a Diagnosis	Phase in Treatment Trajectory	Type of Chemotherapy	Patient had Emergency Treatment	Type of Adverse Event
			lymphoma	previously on ‘watch & wait’		going			Sepsis
CW1	Male	50-59	Haematological – multiple myeloma	6 months	Delayed	Just completed treatment	Oral	Yes	Neutropenic Sepsis
CW6	Female	60-69	Lower GI.	A year	Not discussed	Treatment on going	Intravenous (IV)	Yes	Not stated
CW7	Male	Over 69	Lung	Over a year	Delayed	Treatment on going	Both IV & Oral	Yes	Arrhythmias
CW8	Female	Over 69	Lower GI.	Over a year	No reported delays	Treatment on going	Both IV & Oral	No	N/A
CW9	Male	Over 69	Lower GI.	A year	Not discussed	Treatment on going	Intravenous (IV)	Yes	Breathing Problems
CW10	Male	50-59	Haematological - lymphoma	10 months	Delayed	Just completed treatment	Intravenous (IV)	Yes	Neutropenic Sepsis
CW12	Female	50-59	Breast	18 months	Not discussed	Treatment on going	Intravenous (IV)	Yes	Not stated

Lower gastro-intestinal (G.I.) cancer patients

5.7 The Patient Interviews

It should be noted that while ethical approval had been given to interview up to ten patients, just three were conducted. Concerns regarding the sensitive and distressing nature of these interviews came to fruition. It was also apparent that interviewing more patients would not have provided any further data for the purposes of meeting the aim of this study, than that elicited from observations and the uncountable informal conversations held with patients during the fieldwork. However, the quotes obtained through in-depth interviews with the three patients have been used in this chapter to illustrate many of the findings of the informal interviews/conversations held with patients during the fieldwork.

Three interviews were conducted with patients between August and September 2012. These patients had been followed throughout the treatment trajectory. Their nurse-led information sessions and on-treatment consultations prior to each cycle of chemotherapy had been observed. Two patients (P1 & P2) attended on their own for treatment. P1 attended all visits for whatever purpose, alone. P2 brought her husband for the '*important appointments*'. While P3 always brought her husband, she often went in to the on-treatment consultations alone, leaving him in the waiting room.

P1 was interviewed half-way through her treatment period. P2 and P3 were both interviewed at the end of treatment. The interviews lasted between 44 and 103 minutes (mean 75). P2 and P1 both cried during the interview and all three found it difficult to talk about their support persons' experiences. They frequently focused on their own experiences; it was difficult to keep them to the aims of the interview.

Table 13: The Characteristics of the Interviewed Patient Participants

Patient Code	**Site**	**Gender**	**Relationship with Key Support Person**	**Other Social Support/ Family**	**Lives with Patient?**	**Age Range**	**Employment**	**Ethnicity**	**How/Where interview was conducted**
P1	2	Female	Patient's mother	Large family, daughter (11) friends & work colleagues	No	30-39	Nurse: Working full-time but on sick leave	White British	By phone
P2	1	Female	Patient's Husband	Mum & Dad, son (8), friends and work colleagues	Yes	30-39	School Helper: Working full-time on sick leave during treatment	White British	By phone
P3	1	Female	Patient's Long-term Partner	Large family 2 daughters (one lived in the USA) 7 grandchildren Work colleagues & friends	Yes	Over 69	Office Manager: Took early retirement due to illness	White British	At patient's home

Table 14: The Patient Participants' Disease & Treatment Information

Patient Code	**Time Since Diagnosis**	**Type of Disease**	**Type of Chemotherapy**	**Phase in Treatment Trajectory**	**Patient had required emergency treatment**	**Type of Adverse Event**
P1	3 months	Breast	Intravenous	In treatment	Yes	Neutropenic Sepsis
P2	12 months	Breast	Intravenous	End of treatment	No	N/A
P3	18 months	Lower GI	Intravenous	End of treatment	No	N/A

5.8 The Staff Interviews

Twenty-two interviews were conducted with healthcare professionals. Twenty-one of these were with staff from across both research sites. One further interview was conducted with a senior nurse with overall responsibility for cancer service delivery across the region, including those at the Trust. The staff interviews were conducted between February 2012 and August 2012. All interviews except one were conducted face to face, one was at the health professional's home, all the others were in the health professional's work environment, usually in a clinic room or in an office. Three of the interviews on Site 1 were conducted in a store cupboard due to lack of space. One interview was conducted on the telephone. The interviews lasted between 25-101 minutes (mean = 54).

Some of the staff became emotional when discussing challenges the Trust was facing and carers' needs. One interview was stopped when a member of staff broke down and cried. She later explained that she had experienced a very difficult time caring for her Dad when he had received treatment for cancer. Healthcare professionals tended to focus on patients rather than carers. I would have to remind them by re-phrasing questions or asking *'are you referring to the carer or the patient?'* It was common for conversations to continue after the interview and these were recorded in field notes.

The sample consisted of seven clinical nurse specialists (CNSs), five chemotherapy day unit (CDU) nurses, 2 CDU support workers, four senior nurses (who had advanced practice or leadership roles) a dietician and three senior doctors (two oncologists and one haematologist) (Table 15). It should be noted that in this chapter very generic terms have been used to describe roles when presenting verbatim quotes from healthcare professionals, for example, all doctors are called doctors and nurses in the CDU, regardless of seniority, are described as CDU Nurses.

Most of the interviewed CNSs worked on Site 2. Their offices were on the unit; they were more visible and easier to access. I also had a 'hot-desk' space in one of their offices. As a result these CNSs were more informed about the study and wanted to help. Conversely, most of the CNSs on Site 1 were based away from the unit and came under the management of the Surgical Directorate rather than Cancer Services. They were harder to locate and although happy to talk informally, appeared reticent about being formally involved. Three CNSs on Site 1 who were approached for the purpose of interviewing declined to participate, citing work pressures. Two CDU nursing staff declined to be interviewed, one refused to give a reason and the other declined because of personal caregiving experiences, believing participating might be *'too close to home'*.

Table 15: The Characteristics of the Interviewed Healthcare Professionals

HPs Code	Role	Age Range	Sex	Site	Years in Role	Level of Education	Chemotherapy Educated
S2:10	CNS	31-40	F	Site 2	5-10 years	Degree Cancer Nursing	Chemotherapy Educated
S2:11	CNS	41-50	F	Site 2	more than 10 years	Diploma Nursing	Not Chemotherapy Educated
S2:12	CNS	41-50	F	Site 2	5-10 years	MSc Advanced Practice	Not Chemotherapy Educated
S2:16	CNS	31-40	F	Site 2	5-10 years	Degree Cancer Nursing	Chemotherapy Educated
S2:9	CNS	31-40	F	Site 2	5-10 years	Degree Cancer Nursing	Chemotherapy Educated
S1:4	CNS	Older than 50	F	Site 1	more than 10 years	Degree Cancer Nursing	Chemotherapy Educated
S2:24	CNS	41-50	F	Site 2	1-5 years	Diploma Nursing	Not Chemotherapy Educated
S2:18	CDU Nurse	31-40	F	Site 2	1-5 years	Degree Cancer Nursing	Chemotherapy Educated
S2:2	CDU Nurse	31-40	F	Site 2	1-5 years	Diploma Nursing	Chemotherapy Educated
S2:5	CDU Nurse	41-50	F	Site 2	more than 10 years	Degree Cancer Nursing	Chemotherapy Educated
S1:23	CDU Nurse	41-50	F	Site 1	1-5 years	Degree Cancer Nursing	Chemotherapy Educated
S1:2	CDU Nurse	41.-50	F	Site 1	5-10 years	Degree Cancer Nursing	Chemotherapy Educated

HPs Code	Role	Age Range	Sex	Site	Years in Role	Level of Education	Chemotherapy Educated
S1:3	CDU Support Worker	Older than 50	F	Site 1	1-5 years	N/A	N/A
S2:4	CDU Support Worker	41-50	F	Site 2	1-5 years	N/A	N/A
S2:6	Senior Nurse	Older than 50	F	Site 1/2	1-5 years	MSc Advanced Practice	Chemotherapy Educated
S2:8	Senior Nurse	41-50	F	Site 1	1-5 years	MSc Advanced Practice	Chemotherapy Educated
S1:31	Senior Nurse	Older than 50	M	Site 1/2	5-10 years	MSc Advanced Practice	Chemotherapy Educated
S2:23	Senior Nurse	41-50	F	Site 1/2	1-5 years	Diploma	Chemotherapy Educated
S1:26	Dietitian	21-30	F	Site 1	1-5 years	Degree	N/A
S1:25	Doctor	Older than 50	M	Site 1	more than 10 years	Not provided	N/A
S1:30	Doctor	41-50	M	Site 1	1-5 years	Not provided	N/A
S1:24	Doctor	41-50	F	Site 1	5-10 years	Not provided	N/A

5.9 Initial Observations of the CDUs

The initial observations obtained an understanding of the rhythm of the unit and working day for staff, patients and those accompanying them. Early morning CDUs were very quiet and staff would prepare for the day. As patients arrived, workloads increased, and the environment would feel crowded. Staff frequently told me their workload was '*relentless'* and they were '*spinning plates*'. Staff had few breaks during the day and lunchtime meals were eaten quickly. The organisation of work in the CDU was referred to by some staff as a '*factory line'*; patients would come in, have their treatments and then go home. Initially very little interaction was observed between nurses, patients and visitors. One participant acknowledged:

> *'It felt like all I did yesterday was chuck drugs at people, it wasn't a good feeling.'* (CDU Nurse, S1:2)

Nurses working in the CDU were pulled in many directions and frequently interrupted. The phone rang constantly; calls were either from patients or carers asking for advice or from others in the organisation needing information, such as pharmacists. Interruptions to the unit also occurred when patients had allergic reactions to treatment. This required all nurses to stop whatever they were doing and respond immediately to the patient. These events occurred at least once a day. CDU nurses were always on alert for these adverse events as '*things can go wrong really quickly*' (CDU Nurse, S1:23).

Patients also came without prior notice to the units seeking advice about side-effects or were clearly very unwell and needed immediate medical attention. Many patients and carers would wait until the unit opened before telephoning rather than seek advice from out of hours 'on-call' teams or go to Accident and Emergency Departments. Doctors and nurses were often frustrated by this and would comment *'but I told them to contact the hospital'* or *'I told them to go to A&E'.*

Many conversations, initiated by staff, focused on what was happening at the Trust, the merger of sites and constant changes to the service. Staff at both sites would often ask me *'what are they like over there on the other site?'* To which I would respond *'just like you',* because they were. An important finding, during the fieldwork, is that there were very few notable differences between the sites, staff, and organisation of work or indeed patients' and their visitors' behaviours while attending the units. However, there were two significant differences. As previously highlighted, there was a difference in how CNS teams worked across different sites, their location to the unit and how accessible they were to CDU staff. The CDU staff at Site 2 could easily locate CNSs if they required advice about patients in their care. Conversely, Site 1 CDU staff had less contact with many of the CNSs. Although there were exceptions, two CNS teams at Site 1 were very well known by CDU staff and patients. The second most important difference was Site 1's CDU had a much more stable workforce than Site 2. The CDU manager at Site 1 had been there for some time and was extremely experienced; alternatively the CDU at Site 2 experienced changes to the management team during the study.

Often staff members would get upset when talking to me and would admit they found the uncertainty of change to the organisation extremely stressful. Those who had worked there for a long period of time felt the changes had significantly and detrimentally impacted on, the amount and quality of care they provided.

Some of this did not make sense because conversely patients and visitors (on both sites) would tell me '*they're lovely here'*. When asked why they thought this, the patients said it is because *'they know me'* and the staff worked hard to keep things *'normal'* for them. Healthcare professionals having a sense of humour was an important aspect of keeping things normal for patients and their visitors.

> *'Well I think it was just that they obviously all got a fairly good sense of humour which helps and there's always banter, banter between the staff and with the patients as well'* (Patient P2)

5.10 How the Work Is Organised

Patients were referred to the unit from either their GPs or other services within the Trust, such as lung clinics or A&E. Once a patient is diagnosed the disease specific multi-disciplinary team (MDT) decided whether a patient should be treated with chemotherapy. This was determined by a number of factors, including the type and stage of disease, and whether patient was physically fit for treatment.

Patients would meet the oncologist, receive information and consent to treatment. These meetings were relatively short, between 10 and 30 minutes depending on the complexity of the diagnosis and the number of patients the doctor had to see. Clinic lists could be large. Each doctor could meet up-to twenty patients a morning. Generally CNSs would attend these consultations or be available afterwards for the patient and their families.

Before starting treatment, patients would attend a pre-chemotherapy consultation or assessment, often described by staff as the '*chemo chat'* or the '*work-up*'. These sessions, time permitting, occurred a week before treatment began and were mostly conducted by CDU nurses (on site 2 the haematology CNSs also did these consultations). The nurse provided a lot of information to the patient on what to expect, how treatment was administered and potential side-effects.

> *'The new chemotherapy assessment that we've got, we've literately got to tick to say yes you've giving them this, you given them that, they've got to sign it to say you've given the information well you can spend all the time just, you're not actually talking to the patient, you're just like almost telling them, barking at the all these things just because you have to tell them which doesn't make it very personal.'* (CNS, S2:16)

Immediately before starting each cycle of treatment the CDU nurses at Site 1 would do a pre-treatment chemotherapy assessment (on-treatment review), usually conducted in private. At Site 2 assessment usually took place while the patient was being prepared for treatment in the main CDU room. However, a very similar on-treatment review was also completed by the medical team either the day before or on the same day as treatment. These reviews focused on assessment of chemotherapy side-effects and toxicities. Very little systematic assessment was observed of patients' psycho-social needs. Carers were not formally assessed at all. Assessment prior to having each cycle of chemotherapy was described by patients, carers and some healthcare professionals as a '*tick box exercise*',

> *'They (nurses) would go tick, tick, tick.' (Patient, P3)*

> *'But in real terms is it a tick box exercise or are we actually addressing the needs of patients?'* (Senior Nurse, S2:8)

Patients grumbled that they often had to repeat these toxicity assessments with different members of staff. One doctor acknowledged that this lack of co-ordinated assessment during treatment was a problem and needed addressing,

> *'And I think some people find all these checklists about information and things quite annoying but I think actually having some footprints as we develop all of these things so that we're not repeating, the kinds of things patients really hate are going through the same thing again and again and people not being aware of the discussions that they've had previously. So we need much more sophisticated ways of having a record of that.'* (Doctor, S1:25)

The amount of time patients stayed on the CDU could be between 10 minutes or more than six hours depending on the treatment they were having and whether they were well enough to go home once treatment had been administered. Waiting times were often long, due to large patient numbers, emergencies occurring on the unit or because treatments had not been prepared and delivered in time from pharmacy.

5.11 Who Comes With the Patients?

During the first few weeks of observing in the CDU, a simple record (audit) was kept of who attended with the patient, why the visitors were there, which health professional attended to the patient and visitor's needs, and if the patient attended alone, for what reason. This audit data was recorded on nine separate observation episodes at Site 1 and five at Site 2.

Table 16 below presents the data collected in one observation period at Site 1 and is representative of all observation episodes in both CDUs. It can be seen that patients often came alone; reasons included the carer was working, it was boring for the carers, '*I would have to entertain them'* (Patient, P2) and one male patient during the fieldwork admitted,

> *'I'm trapped here, hooked up to this thing, if she came; she* [wife] *would only nag me about decorating the house and getting new carpets'.* (Male Patient)

Another patient admitted that the hospital was the only place where she could be really honest about how she felt. She wanted to hide her distress from family or friends and did not want them there with her.

> *'I tended to break down more when I am hospital than I do at home'* (Patient, P1).

During observations a number of patients admitted that they did not have anyone to come with them or they had refused to tell family and friends they were ill. Many of the CDU nurses were often unaware of this. One male patient told me that *'they're interested in me here but not really the wife'*. Many of the patients who came alone said they brought people with them to the *'important appointments'*. These were defined as meetings where significant information was likely to be given.

People, who came and stayed with the patient during treatment, gave a number of reasons including company for the patient and/or seeking reassurance the patient was being looked after properly. Many visitors said that they came to watch and listen to what was going on, especially when the patients had just begun their treatment as they *'were often uncertain and did not know what to expect'.* Some carers disclosed they came on the first cycle of chemotherapy, once reassured the patient was receiving good care and was '*safe*', took the opportunity to have some time alone. Relatives and friends of the patient often found the environment unwelcoming. One carer provided the same description of the CDU at Site 2 as a nurse (page 127):

> *'Well it's very crowded there, no it isn't [welcoming], I go away and come back when I know he's going to be nearly going to be finished because it's, there isn't a lot of room there, and they're manoeuvring about and I remember once being there, I'd only been there, I wasn't there for very long, and the filing cabinets were there, and the secretaries were coming in to file notes, and you were constantly moving, no it isn't a great place to be hanging around.'* (Wife, CB4)

Table 16: Audit Data: CDU

Patient/ Gender	Date	Accompanied by Family/ Friend	Relationship to patient	Reason for attending/not attending	Attending Health Professional	Services/ Information Offered to Family/Friend
Male	27.9.11 am	Yes	Son and friend	Company	Nurse providing treatment	None
Male	27.9.11 am	No	N/A	Patient had not told relatives	Nurse - treatment	N/A
Male	27.9.11 am	No	N/A	Works	Nurse - treatment	N/A
Male	27.9.11 am	No	N/A	Works	Nurse - treatment	N/A
Female	27.9.11 am	No	N/A	Works	Nurse - treatment	N/A
Male	27.9.11 am	Yes	Partner	Patient very anxious and unwell subsequently he was admitted to inpatients	Both	Reassurance And Explanation
Female	27.9.11 am	Yes	Partner	Company	Nurse - treatment	None

As previously highlighted, patients told me during observations that they were more likely to bring relatives or friends to *'important meetings'*, consultations where significant information may be exchanged. Table 17 below, is an example of one observed doctor led on-treatment clinics. It can be seen that the patients' relatives were not acknowledged during this meeting. This was not an unusual occurrence. The patients' companions were rarely acknowledged in any patient and doctor and/or nurse consultations (formal meetings) observed during the fieldwork.

Table 17: Audit Data: Consultant led On-Treatment Clinic

Patient	**Date**	**Was Patient Accompanied**	**Relationship to Patient**	**Reason for Attending**	**Attending Health Professional**	**Family member/ friend acknowledged**	**Services/ Information offered to carer**
Female	18.1.12	Yes	Husband	Listen	Medical Oncologist (Onc.)	No	None
Female	18.1.12	Yes	Mother	Listen	Medical Onc.	No	None
Female	18.1.12	No	N/A	N/A	Medical Onc.	N/A	N/A
Female	18.1.12	Yes	Husband	Listen	Medic Onc.	No	None
Female	18.1.12	Yes	Sister in-law	Listen	Medic Onc.	No	None

5.12 Carers and Patients Initial Reactions

The interview findings revealed carers' initial reactions to hearing that their relatives had been diagnosed with cancer were of shock or relief. Shock because they had not expected it or relief because their relative had been experiencing unexplained symptoms for a number of months.

> *'Yes like a bulldozer, you know when you feel it's like a bulldozer hitting you straight in the face'* (Daughter, CB3)

When there had been a delayed diagnosis relatives were also angry. Blame was usually directed at the patients' general practitioners (GPs) for not identifying the cause of the symptoms quickly enough. The delays left these carers with a sense of mistrust in the healthcare system, adversely affecting their confidence in healthcare professionals throughout the patients' treatment pathway.

> *'I was annoyed with the doctor; I was absolutely furious, livid. If I could have had the doctor's throat in my hands I probably would have wrung his neck because it shouldn't*

> *have gone on so, and I said to the doctor my brother has been in agony for 10 months, why hasn't something been done about it? You do not keep a dog in agony for 10 months.'* (Brother, CW1)

Carers described how the patients' diagnosis literally '*turned their worlds upside down'*; creating a sense that nothing would be the same again.

> *'I've been saying to my boyfriend, I do not think that I'm going to feel Ok again, I can't imagine how I'm just going to just feel normal, and I felt that for about three weeks, and I was just going through, going to my job, and I just couldn't see how I would just go back to feeling that I could appreciate things, or feel happy or anything.'* (Daughter, CB2b).

Carers acknowledged that their biggest fear was of the '*unknown*' and whether their loved one was going to die. Thus, they reacted with mixed emotions when they heard the patient was to have chemotherapy. Relief there was a plan and a sense of '*let's get on with it*' but also that it would be difficult and some described feeling '*frightened*'. One carer described how in the beginning she did not know what chemotherapy was:

> *'I didn't know anything about it. I thought chemo was a machine. Yeah. I thought it was a, you know like the, when you go in that tunnel machine, I had one a while back, and that's what I thought it was. I didn't think it was tablet and intravenous stuff, I didn't know.'*(Wife, CW7)

Conversely, those patients I talked with during the observations told me their initial reaction for the need to have chemotherapy was acceptance. Although they recognised that chemotherapy was a '*scary*' word and evoked images of people being really sick and losing their hair they felt that '*they had to get on with it'*, as illustrated in the quote below from one interviewed patient

> *'I'll be quite happy to take it because if that's my insurance policy, if that's what I have to go through to get rid of everything then so be it'* (Patient, P3).

Patients and carers, during both informal and formal interviews, described having misconceptions and anxieties about chemotherapy side-effects; especially if they had little recent experience of treatment basing judgements mostly on what they had seen in films or in the media. However, carers who had recent experience of other family members or friends having treatment knew treatment would be difficult, but could be manageable. Side-effect fears included: the patient would be extremely sick, in pain and lose their hair. From the point of diagnosis, knowing, how best to support and help the patient was one of the biggest challenges for carers.

5.13 Being Prepared for Treatment

Preparation for some participants occurred quickly after the patient was diagnosed while others had longer to adjust as chemotherapy began after surgery. For most, however, being prepared for chemotherapy occurred during the pre-chemotherapy consultations with doctors (for consent) and nurses (information session).

None of the patients and carers could clearly remember the pre-chemotherapy consultation without prompting. Very few patients read the information provided by the service or sought more information. If they did seek further information it was generally from family members or friends they could trust, with either professional or actual experience of chemotherapy. A patient (P2) described how her husband read all the information given to them; she preferred not to know what might happen, managing any problems as they arose. Carers and patients during the informal and formal interviews conducted in this study often acknowledged that little could prepare you for the effects of chemotherapy. They recognised preparing people effectively and tailoring the information to individual's needs could present a challenge for healthcare professionals. The phrases '*everyone is different'* and '*everyone reacts differently'* were often heard.

Carers recalled that initially the patients received an overwhelming amount of verbal and written information. The carer would read and try to make sense of this, either alone or with the patient. However, most carers did not feel prepared nor knew what to expect. They also did not realise the extent of the role they would need to undertake or the responsibilities they would have. Those who did, had previous experience and knowledge gained from a family member or friend receiving chemotherapy. Carers did not receive specific information targeted at their needs or were offered advice on how to help the patient while they were having chemotherapy. Indeed carers were rarely acknowledged by healthcare professionals or asked to contribute in these pre-chemotherapy meetings.

> *RV: 'Were you offered an opportunity to talk about your concerns about Jane[3] and her care'*
> *Interviewee: 'No not really, no.'* (Husband, CW6)

The next section presents an excerpt from the observation fieldwork transcripts of a pre-chemotherapy consultation. Although, the patient attended alone the nurse did not assess whether the patient had support at home.

5.14 The Story of Lee

I joined Annie[4] (CDU nurse) to observe some pre-chemotherapy consultations. The first patient was Lee[5] a 37-year-old who had been diagnosed with Breast Cancer and had already undergone a mastectomy. She was also a recently qualified nurse. Annie started with asking Lee how she was; '*ok*' and then Annie introduced herself. She told Lee that she would be using the patient information sheet as a guide and go through everything with her. Annie then went ahead, giving information. She did not check with Lee what she already knew and what she wanted to know. No assessment of what Lee understood or felt about the treatment took place. Annie did not explore why Lee had come on her own or whether she had support at home. Lee was very talkative to begin with then started to offer less. Although she kept smiling and saying she was ok with everything, her body language told a different story. Her leg was constantly jerking up and down, she was tapping her foot and had her arms folded across her body. Annie used terms such as *'unfortunately you will be sick; unfortunately you will lose your hair'* throughout the consultation*.* A lot of information Annie gave appeared to be unnecessary. Annie talked about how Lee must have '*safe sex*'. Lee responded by saying '*I'm not in a relationship'*. Annie said '*well just in case'*. Lee said *'I have an eleven year old daughter and I do not want more nappies'.* The information offered by Lee was completely ignored by Annie who continued to read through the treatment information sheet. Lee had read this information before coming to the consultation.

At the end Annie needed to go and check the diary for Lee's appointment. When she had left the room I asked Lee if she was ok, '*I'm fine, I just need to get on with it'*. We talked about her job

---

[3] Jane is a pseudonym
[4] Annie is a pseudonym
[5] Lee is a pseudonym

and her training she said she was really upset about having this disease, she wanted to get on with her life and she '*loved*' being a nurse.

Lee (P1) was formally interviewed ten weeks after her pre-chemotherapy consultation. Initially, when asked about the information she had received, Lee could not recollect the consultation with Annie. After giving her a brief explanation of the meeting, she acknowledged she could remember very little of what Annie had told her. She recalled that her concerns had not been addressed; the main one was that her treatment would need to be delayed because of poor venous access. As a single mother she had significant responsibilities. A delay would have an impact on her ability to return to work and earn money.

> *'Yes that's it, I remember now, yes. I did feel that I wasn't taking any of that in what she was saying because she was going through literally every side effect wasn't she? I didn't take anything in, obviously. Didn't take any of that in, I think my main concern that day was because she said she couldn't get any veins'* (Lee*, P1)

Lee did experience neutropenic sepsis after her first cycle of treatment. Her family had been unaware of the seriousness of this adverse effect until she was admitted to hospital. Lee did not want to involve her mother (identified as her main support person) because she thought she would be able to manage herself. In hindsight she realised that she was probably *'too independent for her own good'.*

Annie had been formally interviewed two weeks before the observation took place. In the quote below she describes her understanding of the pre-chemotherapy consultation. From the findings presented above it is apparent that there was a disparity in how Annie had conducted the consultation and her beliefs of how it should be:

> *'It's actually a pre-chemotherapy assessment so we go through everything, chemotherapy information, if they understood why are they having it, what support do we give them, why they are having their treatment, what goes on during the treatment, after the treatment and what is the doctor's role and obviously while they are on it, when they go home what are the advice or contact numbers they need to find out. Part of the chemotherapy assessment we ask them with regards to if there is any other people who can be able to help them or if there is anyone who would like further information about what they're having and what other support that the Trust or the Macmillan, which is part of the Trust, can be able to give them'* (CDU Nurse S2:2)

5.15 Experience of and Living with Chemotherapy

For carers the reality of treatment was different from their pre-conceived notions of chemotherapy. Patients were not sick all the time (vomiting) as they thought they might be. Fatigue and lack of appetite were frequently raised as worrying side-effects. What carers did not anticipate were patients' fluctuating and intense mood changes, defined by one carer as an *'emotional rollercoaster'.*

The reality of undergoing chemotherapy was also different from patients' initial pre-conceived ideas. Patients expected to feel a lot worse and during the fieldwork reported that they had undergone a relatively easy time in comparison to other patients. So it was surprising when they later recounted, during both informal and formal interviews, experiencing quite significant side-effects including nausea and vomiting, anorexia and fatigue. However, they had been surprised by their erratic emotions and by changes to their body image, particularly weight gain.

While carers often talked about the treatment period 'being a long haul', patients felt that the time went quickly. For patients remaining in the present and living day-to-day appeared to be a coping mechanism. Patients reported that they '*had good days and bad days*' with side-effects fluctuating. Carers found these fluctuations difficult to manage and reported not knowing when to step in and help, or when to step back. Patients recounted getting irritated with their family members because they were interfering by taking over the cooking, or worrying too much about what they ate. On good days patients tried to do what they normally did, such as shopping, cleaning and taking their children to school. Maintaining a sense of normality for themselves and for their families wherever possible was extremely important to patients. Carers recounted how patients often got bad-tempered with them and that they frequently '*got things wrong'*.

> *'Yes, he gets fed up that he can't do things for himself and some little thing I say might just hit a nerve with him, so he'll start getting mumpy, so be mumpy, just get on with it.'*(Wife, CB4)

Carers would be led by the patient. Remaining vigilant to how the patient was feeling then determined how the carer should '*play it'*.

> *'I just see what's best to do for him, how he feels, what he wants to do, if he feels fine we go out for a run in the car, you know we get out into the countryside or whatever, but if he doesn't I just keep it quiet and get on with my sewing and let him sleep.'* (Wife, CW7)

Feeling uncertain was a key theme throughout the carer interviews. They were uncertain about how the patient would react to treatment and what side-effects they would experience; this heightened the sense for carers of being on constant alert.

Most of the patients and carers who participated in the fieldwork had experienced adverse effects of treatment whilst at home, requiring advice and support from the hospital. Patients having signs of an infection (pyrexia) created great anxiety for carers and they described feeling distressed when they saw the patient unwell. Initially they did not know who to phone at the unit. However, when these events occurred most carers did not hesitate to seek advice on behalf of the patient by contacting the hospital. Some reported, however, that frequently they needed to be quite firm and assertive with the patient.

> *'We said to her, as in myself and Bob[6], you need to go to the hospital to get it checked, and she said no and left it overnight, and overnight it became quite serious, so that when she did go to hospital, they said you know, if you'd left it much longer you could have become seriously ill,'* (Daughter CB2b)

Throughout the fieldwork, patients acknowledged that carers sometimes needed to be assertive with them, especially when the patient was experiencing side-effects and was reluctant to seek professional advice. Carers reported this was because patients were frightened of what the side-effects might mean. Tensions arose between patients and carers, often because patients would not seek advice or admit they were having difficulties, for fear that chemotherapy would be stopped.

Patients told me they also did not want to '*bother*' the professionals as they perceived them to be too busy. They did not want to seek advice from their GPs or go to A&E, preferring to have advice or help from professionals who knew them and their treatment. Patients thought side-

---

[6] Bob is a pseudonym

effects were an expected consequence of chemotherapy to be endured or considered the side-effect as not serious enough to warrant attention. Patients during observations and formal interviews reported that while having chemotherapy they often did not know how '*bad or ill they looked'*. Conversely, carers reported being able to instantly observe a change or deterioration in the patient's condition but were not always able to comprehend what this change meant, until there was a clear physical sign, such as a raised temperature.

Patients also recognised that carers were often uncertain about what to do and had awareness that their families and friends needed to be needed. However, patients admitted during the fieldwork that they often made it more difficult for their families, as they frequently blocked their involvement with healthcare professionals, as described by one patient during an interview.

> *'I think because I am not making them involved it's quite hard.' [*For her family*]* (Patient, P1)

Cancer and chemotherapy for patients and their families brings disruption to their lives. Carers reported while the patient was receiving chemotherapy they experienced numerous challenges related to managing their work or other family commitments. They described having to '*put their lives on hold*'. Social activities were curtailed, life for them revolved around the patient and the treatment.

> *'At times it becomes a struggle, your day and your week is just purely devoted to looking and caring after her, and you need a break, and it's very difficult for you to turn round and say I need a break from you… but I just need a break, just getting away for, I go out and about for work, but that's not the same thing as saying well actually I'm going to go out one evening with my mates or whatever it happens to be.'* (Partner, CB1a)

Patients told me during informal and formal interviews that they did not want to be a burden to their families, choosing to play down side-effects or pretend everything was okay. Patients were aware that their disease and the treatment had a significant impact on their families and friends.

> *'So, whereas I'd be quite happily just be getting on with everything. I think it probably hit him harder in some ways because he is that sort of person that just worries about everything. So I think it does depend on the person as to, so I think in some ways it was*

> *like me kind of supporting him in a way rather than the other way round, which sounds a bit odd' (Patient, P2)*

However, carers viewed the cancer experience as a shared experience, *'they were in it together'* and used the word '*we*' throughout the interviews. For patients it was their disease and their bodies that had '*let them all down*' (Fieldwork and interview participants). Patients reported needing to be in control, maintaining their independence. However, these needs often created problems for those supporting them.

> *'Mum's very independent she didn't want me to talk to anyone about her and got upset if she thought I was causing worries or problems she also wanted to control the information… she will say, she would always say oh do not worry, do not fuss, I can do it.'* (Daughter, CW8)

Carers experienced a myriad of emotions during the patients' treatment; uncertainty, fear, frustration, resentment, guilt, feeling trapped and alone. Carers expressed their need for normality to return and having time for them was important. They also recognised the need '*to get on with it*' while at times feeling emotionally exhausted. Carers would hide their feelings from the patient.

Patients recognised that carers often protected them by hiding their own distress or fears about the patient's condition. Conversely, patients protected their family and friends choosing not to share with them their fears, especially of the possibility of dying. Patients, during informal and formal interviews, acknowledged that carers often wanted to know more about the long-term outcomes, but patients blocked discussions preferring to remain in the present, rather than talking about what the future may bring.

Carers did report that they wanted information about the patient's prognosis but did not want to ask questions for fear of upsetting the patient. Talking with the patient about the possibilities of the patient dying was described by carers as '*avoiding the elephant in the room*'. However, they highlighted how having information regarding possible outcomes would help them manage and plan for the future. It wasn't just information regarding prognosis they needed; they had more immediate concerns to do with planning for holidays or managing their working lives. Indeed, for some carers this lack of tangible information was a source of resentment and irritation towards the professionals. They felt that doctors especially withheld information at the beginning of treatment which would have helped them manage better over the long treatment trajectory.

> *'We're all planners, we're a planning family - we like to have everything organised and stuff so it's when suddenly you get new information that kind of you think oh why wasn't I told that to begin with.'* (Daughter, CB2b)

For many patients the end of treatment was significant and evoked feelings of uncertainty and fear. Conversely, carers looked forward to treatment ending and '*getting back to normal*'. Having the treatment and going to the CDU helped patients to '*feel safe'*. The quote below from a patient interview is representative of many conversations in the fieldwork.

> *'I would have gone in and sat in the chair even if nothing was being done because it was like your sanctuary. I think because you're there and if anything happens you'll be dealt with straight away that first of all makes it a safe haven if you like and then of course all the nurses and the receptionist are so nice, they just all know you.'* (Patient, P3)

From the findings above it is evident that carers experienced numerous challenges when supporting people who are having chemotherapy. When interviewed most healthcare professionals were able to describe the challenges carers experienced. Table 18 below, provides examples of these challenges from the perspectives of patients, carers and healthcare professionals (gained through both formal and informal interviews). Where there were no findings to support, boxes have been left empty.

Table 18: Carers' Challenges

Patients	**Carers**	**Healthcare Professionals**
Me (independent)	The patient wants or needs to be independent – they will not ask for help	The independent patient
They need to protect me	Managing the patients' emotions	The patients' emotional reactions are difficult to manage
They worry and are distressed about me	Managing my own emotions	Experience the same emotions as patients

Patients	**Carers**	**Healthcare Professionals**
I do not want to burden them	I cannot disclose how I feel	Being open and honest with each other
They need to be needed	I need to support them – it is what you do	They need to be needed
They do not know what to do	I do not know what to do or say – I felt helpless	They do not know what to do
I need to pretend everything is ok	Managing uncertainty about what will happen	Managing uncertainty about prognosis
I do not like people knowing	They do not want me to talk to people about them	Communication difficulties
I can talk for myself	I want them to have the best care	Wanting the best for their loved ones
They do not understand what it is like for me	I feel one-step removed and I struggle to understand	It is hard for them to see the patient so ill
	The patient doesn't understand what it is like for me	Patients can be self-absorbed
It went quite quickly	Treatment is a 'long-haul'	Treatment goes on for such a long time.
I was not aware when I was really ill or how bad I looked	I struggled to understand what the signs and symptoms were or meant	Understanding what is 'normal' and what is not
I was not aware of what was going on	He/she (patient) is vulnerable and often in a 'trance'. I needed to protect them.	They protect the patient
	They (patient) and HPs assume I will take on this role	'We do not tell them how important they are'
I can manage	They (patient) block me from helping	Patients' perceptions of the carers role
I did not see how ill I was	I find it difficult if he/she is	Seeing the patient being ill

Patients	Carers	Healthcare Professionals
	ill	is hard for them
	I do not live with them (patient)	Not living close to the patient
	Healthcare professionals speak a different language	They do not understand medical terminology
	Taught myself to give injections and medicine	They become a nurse (with no training)
	I get confused about the organisation of care and HPs' roles	
I do not want to know too much	I need to know and want the information but it is not always forthcoming	
The information is overwhelming at times	I feel overwhelmed with the information	There is a lot of information
	I struggled to understand and translate the information	They find the information difficult to understand
I had everyone supporting me	It's not about me it is about them (patient)	Our focus of care is the patient
I do not want to know too much and need to stay in the present	I need information about what the future may hold so I can plan for holidays and life.	Carers want to know about the patients' prognosis
I want to carry on as normal	They (patient) need to feel normal	They put the patient's needs first
	I have to manage other commitments	Juggling other commitments
	I worry about money	Financial worries
They need to learn new roles e.g. cooking	I need to learn new roles	Negotiate roles
They worry about what I eat	I worry they do not eat	Food and diet cause tensions
I did not want to go to	They will not do what they	Patients will not always do

Patients	Carers	Healthcare Professionals
hospital or bother HPs	should	what they should
I need to get on with it	They are not always truthful about side-effects	The patient is not always truthful
I need to get on with the treatment	I want to go on holiday but it is difficult to plan	They need to figure out how to organise their lives
	I want to have a social life but I feel guilty	They have their own lives to lead
I block their involvement	They stop me from being involved	Carers walk on 'egg-shells'
I need to stay in the present	I'm frightened they will die	They want to know the patient's prognosis
	I dread the weekends	
I needed to get on with it	I was uncertain about the worth of treatment	The patient wants the treatment

5.16 Carers' Roles

From the findings above it is also evident that carers undertake numerous roles to support patients while they are having chemotherapy. In the interviews, carers often found it difficult to articulate what they did. Patients, when asked in the formal and informal interviews, found it even harder. However, they acknowledged that their family and friends '*did everything for them*', when they, themselves felt unable to manage. One patient, when asked what would help patients manage better at home, recommended '*have a Ted*[7]*!*' (P3). In other words, make sure patients have someone like she had (her partner) to support them at home.

Healthcare professionals found it easier than carers to articulate the roles family and friends adopt. While, CNSs had a greater insight into the roles carers assume than participants from other health professional groups.

---

[7] Ted is a pseudonym

> *'I think they're invaluable to be honest with you, I think people leave the hospital, they often do most of their deep thinking and concerns and worries and we are very lucky if we see 10-20% of that, that they come back to us and tell us about it, I think informal carers or carers per se are exposed to a heck of an awful lot more queries and concerns than we ever will be as healthcare professionals.'* (CNS, S2:12)

It can be seen in Table 19 below, reporting findings from both the observations and interviews, that there was agreement on most of the important roles carers adopt between the three groups. There were also anomalies. Healthcare professionals did not identify the important supportive role of maintaining normality and providing humour. Patients did not identify carer roles such as 'seeker of advice' or 'monitors' of side-effects. This could be because the patients who were interviewed were very independent and generally sought advice from the hospital themselves. Neither patients nor healthcare professionals identified the carers' role of managing finances. However, both these groups identified the financial challenges created for both patients and their families because patients were often unable to work. Some healthcare professionals (mostly CNSs) viewed carers as an integral member of the team. Whereas, carers viewed the partnership between the patient and themselves as a separate team, '*we're in it together*' rather than being a member of the patient's health team.

Neither patients nor carers identified that carers were enablers of treatment. Two of the interviewed doctors and many of the CNSs believed that without the support of carers, treatment could not be provided in an outpatient setting and patients would not be safe at home.

> *INTERVIEWEE: 'I think again from my perspective it's very helpful or I feel a lot better if there is a good carer support system looking after the patient when they're having chemotherapy. And in fact if you have somebody who is not very well themselves who has a lot of co-morbidities and doesn't have carers, doesn't have somebody that lives with them or at least somebody that they can contact and who can be there very quickly, I would be very loathe to give chemotherapy.'*
> *RV: 'OK, I was going to ask if it influences your decisions.'*
> *INTERVIEWEE: 'Yeah absolutely influences the decision.'* (Doctor, S1:24)

Table 19: Carers' Roles

Patients	**Carers**	**Healthcare Professionals**
Providers of practical care e.g. housework, driver, childcare	Providers of practical care	Practical helpers
'They do everything'	'You do whatever you can'	24/7 Support
Emotional support	Emotional support	Emotional Support
Protects	Protectors	Protectors 'a safety net'
Buffer the affects e.g. on body image		
Fun	Humour	
Normality keepers	Normality	
To listen	To listen 'a pair of ears and eyes'	'A pair of ears'
Information gather	Information gatherer	Information gatherer
Information processor	Information processor	Information processor
	Seeker of advice from the hospital/HPs	Will contact for advice
	A link between hospital and home	A link between hospital and home
	Recorder of information or diary keeper	Writes notes and keeps an account like a 'personal assistant'
	Monitoring and managing side-effects or symptoms	Monitors and manages side-effects or symptoms
	Plans	Planners
	Encourager	Good prompters
	Managed medicines or injections	Manages medicines
	Manages finances	
Assertive	Being assertive	Assertive
		Complainers
	Advocate for patient	Advocate

Patients informed me during informal and formal interviews that family and friends provided practical help, such as, shopping, cooking, cleaning, driving to appointments and childcare and emotional support. Numerous fieldwork patients described how they felt an important role carers undertook was keeping things normal and seeing humour in the situation they were in, blunting, and protecting them from the effects of the treatment. These patients' beliefs are encapsulated by a quote taken from one of the patient's formal interviews,

> *'We did have a laugh sometimes about what was going on and how bad I looked and everything. But again it's not until afterwards when he says you really did look unwell.'* (Patient P2)

Both carers and healthcare professionals identified the role of carers being an advocate for the patients.

> *'Needing that patient to have the best at the right moment in time, they can't bear the thought that they might be upset; the patient might be upset or anything so they take on everything for that patient. They are like the guardian angel in front of you….Fighting for them or advocating for them or definitely even if they haven't been asked to, being the mouthpiece for them.'* (Senior Nurse, S2:6)

However, only health providers identified that carers often adopted the role of '*complainer*'. Indeed many of the complaints the service received were not from patients, but from their families. Carers viewed this as an advocacy role rather than a '*complaining*' role.

> *'Patients will complain through a relative but sometimes it may not be that the patient actually has a problem with the service, it will be the relative has a problem with the service and will be about that engagement with that relative or the expectations of that relative and it will be about us not acknowledging that they're a key player or a key carer.'* (Senior Nurse, S2:6).

5.17 Carers' Roles in the 'Important' Consultations

Carers and staff stated that it was preferable for the patient to have someone with them when they attended the consultations where significant information was going to be imparted. These people were expected to come to listen to the information. This was because they could hear '*things that the patient wouldn't hear'* or could ask seek answers for questions the patient would not or had not thought to ask.

> *'I do not know, at what point you tell people things, it's an awful lot to be getting on with isn't it. And the person who has the cancer is only focused on one thing, and what's really*

> *important is that the carer's involved in all the sessions with the oncologist or the doctor or the hospital so that they pick up on the things that probably flowed past them, or you actually ask pertinent questions.'* (Daughter, CB2b)

Patients' relatives or friends were frequently observed writing things down during consultations.

> *'Some people write little notes down when you are talking. They [carers] have their little books out and that's their job in there.'* (CDU Nurse, S2:18)

> *'Oh absolutely, keep a diary of when we've got to go for blood tests, he has an appointment card, but what the blood tests are, if he's got to have his pee tested now, what the process is, whether I've got to take it into the hospital, all that sort of thing, I write it down and keep a diary of it all.'* (Wife, CB4)

As already identified in many of the observed consultations, carers were not acknowledged and practitioners rarely asked who they were or what their concerns were. Nearly all practitioners were extremely competent with the tasks they needed to perform and in their knowledge of the disease and treatments. Nurses and doctors would, for example, talk confidently about side-effects and how to manage them. However, the story of Lee presented in section 5.13 was not an unusual occurrence. Many practitioners offered solutions and false reassurances before really finding out what was going on with the patient and their carer. They also missed the opportunity to demonstrate empathy when patients were clearly upset, by acknowledging how difficult it must be for both the patient and their family. Carers were observed to provide much of the emotional support to patients in consultations. They acted as a buffer and helped when the news was bad.

> *'Because a couple of times when the consultant has said you know the bad news is, you know he* [patient] *sort of turns round and looks at me, but if I wasn't there you just don't look at the nurse that's there or because you don't know, you just want someone that knows about you and can help you at that particular moment.'* (Wife, CW9)

This particular carer was adamant that healthcare professionals had included her in the consultations by using non-verbal communication skills,

> *'Jack*[8] [Patient] *said …. They always include you don't they, I said yes they always make eye contact and I find that that is tremendous.'* (Wife, CW9)

Some healthcare professionals were aware of the challenges carers had, when they accompanied patients to their consultations.

> *'The carer has I think such a difficult, unmet kind of set of needs that they can't ask questions. They can't ask their own questions because the consultation is not geared around them, they can't, they have to walk on eggshells often around their partner because he or she is the one that's, or their mum or dad because they're the one that's ill. But actually their needs sometimes to me are greater.'* (CNS, S2:9)

Some practitioners were observed to demonstrate very good self-awareness, if not overtly, of the situation the patient and their support person were in. These practitioners were willing to actively listen and ask questions. They appeared to have a finely attuned antenna and knew when to take risks; by identifying the cues the patient and their carers were offering and acting on them. As a result they appeared to manage the needs of all those who attended the consultation. While they remained focused on the patient, they would involve the carer in the discussions.

> *'I think it was Jill*[9] *[Nurse] picked up on what I was trying to say and then didn't discuss it any more with mum but then at the end said so we think we're going to perhaps give up on the fruit for the time being and mum said 'oh yes I think perhaps', so the nurse had done it in such a way that it didn't look as if we were ganging up on mum, and I came away thinking, she was able to manage me and mum. It was really clever.'* (Daughter, CW8)

5.18 Patients' and Carers' Perceptions of the Service

Patients and carers, during informal and formal interviews, were positive overall about support the patient received from the service whilst having chemotherapy. They felt that staff went at

---

[8] Jack is a pseudonym
[9] Jill is a pseudonym

times, beyond the call of duty, when caring for patients. Carers identified a number of CDU staff by name as being especially approachable and supportive.

> *'They're just really nice people, very down to earth and they take up their time, some of the time they're meant to finish I think 5.30pm/6pm and they're there after 6pm, 7pm until that last patient has gone. They work beyond their time and through their lunch sometimes.'* (CW12, Daughter)

Many carers could not identify who the patient's site/disease specific CNS was.

> *'We didn't realise that she had a breast care nurse, and that didn't happen until quite late on in the sessions, and that only came about because of some comment she made, well have you spoken to your breast care nurse, well I didn't know I had one, oh yes you've got one, so there's that.'* (Partner, CB2a)

There were exceptions; carers whose relative had either a haematological or lung cancer knew the patients' oncology team really well. Carers would prefer to contact the CNS in these teams first, before talking to anyone else in the service. They had confidence in the CNS' knowledge and knew their concerns would be addressed.

Patients' and carers' complaints about the service were mostly to do with organisational factors. There were frequent complaints about the lack and cost of car parking space. Other complaints were to do with patients needing to travel long distances to regional cancer centres for other treatment or tests. Carers described problems with co-ordination of patients' care and communication between different departments and services.

> *'The uncertainty and the letters being sent and I said to him but you've got an appointment in the other department the same day, so the right hand doesn't know what the left hand is doing and then he'll turn up and his file is down in the clinic that does the bowel stuff, you know, and they've got to go running round looking for it. When you've got all this in your mind it makes it twice as bad, it really does.'* (Wife, CW7)

A disruption in continuity of care was a worrying issue for patients and carers. Patients and carers preferred to be seen by senior doctors and nurses who knew them rather than junior doctors who they felt did not make an effort to know them.

> *'I know they're* [doctors] *pressured and I know they work extraordinarily long hours, but it would save them time if they just took the chance just to flick through the patients notes.'* (Wife, CB4)

Obtaining advice out of hours, at weekends or bank holidays, was problematic for patients and their carers. Carers reported feeling extremely *'unsafe'* and their '*safety net'* was not there, they were unable to contact anyone who would know the patient and treatment.

> *'The only criticism I've got is everything stops at weekends. If you get ill on a weekend or you want help on a weekend forget it, you can't really get in touch with anyone. Answer-phone rules at the weekend I'm afraid. You just have to wait until Monday comes along and you are just left really to work out if it's really bad you have to call the old ambulance, it's the only thing you've got really. But that's the feeling and I think that's the feeling most people of my age have got really when you talk around – don't be ill at weekends is what we say.'* (CW6 Husband)

5.19 What Helped Carers?

What helped carers most, was being reassured the patient was coping well with treatment. Many carers stated *'if they're ok, I'm ok'*. Time, trying things out and gaining experience also helped.

> *'If she's upset I get upset, that's basically what it is really but now she's in a better frame of mind because we're into number three now of the chemo, it's only really early stages but now we know how. Well we didn't know what to expect really in the beginning, I mean we heard about it but now she's gone through it…. That was a big hurdle to get over.'* (Husband, CW6)

Carers disclosed they managed the challenges of supporting someone receiving chemotherapy with help from family, friends and work colleagues. These people supported them in numerous ways, having someone to talk to, away from the patient was valued by carers. For some carers having a strong faith and support from their church helped them cope. As treatment progressed, some carers were able to recognise that cancer was not 'their whole life' and this was important. While others found that going through the experience had made their relationships with the patient and other family members stronger.

5.20 What Preparation and Support Do Carers Need from the Service?

Carers when asked how the service could improve the support for those who supported patients at home, struggled to find an answer. However, carers perceived the most important supportive aspects were to feel reassured that healthcare professionals knew the patient and trusted that the patient was compassionately and competently cared for by the service. However, carers also needed to feel safe. They needed to know from the beginning of treatment, what they could and should do for the patient. They required timely information they could understand, which was tailored and pertinent to their personal situation. They wanted to be acknowledged in their role and for their contributions to the patient's care.

Conversely, some carers thought it was vital that those who support patients at home recognise the important and essential role they perform. Being included in the consultations by healthcare professionals and being involved as part of the patient's team was thus, deemed important. They needed to know who to contact and when they should contact the service, for advice about the patient. They wanted to feel they were not a nuisance, but someone who had genuine concerns about the patient. They wanted reassurance that the person who advised them gave them the right advice. Some carers felt it would have been useful if staff had proactively contacted the patients by telephone, during treatment cycles, to assess how they were doing at home. This they felt would have provided reassurance that they were not coping alone. Some would have found it useful to be offered the opportunity to talk to someone who understood the situation they were in.

> *'I don't know. I mean you can't really ask for reassurance because it's not going to go away and it's not going to get better. Maybe just somebody to talk to, I don't know, I think this is the thing because everybody has got their problems but if you had somebody trained who knew what the process was maybe that would help, I don't know.'* (Wife, IC07)

While some carers (mostly spouses or partners) would have valued an opportunity to talk to a health professional separately from patients, others were adamant that they did not require intervention from healthcare professionals to meet their own emotional needs. They viewed the healthcare professionals as being there for the patient, not for them.

> *'I suppose for me, I would feel like they've got so much to do dealing with the individuals, the patients, you know directly going through it, that I almost feel I wouldn't want to*

> *trouble them, so I don't feel like there's somebody there at that hospital who is there if I've got a questions, I definitely don't feel like that, I feel like if I'm ringing with a question, it would be a question on behalf of the patient, not oh hi, I'm feeling a bit worried today, I just couldn't really imagine me doing that, … I've got no reason to feel this, but I feel like they're under, they've got a lot of work to do and I'm not their problem.'* (Daughter CB2b)

Many of the healthcare professionals were able to articulate in the interviews what carers' needs for support were. Healthcare professionals specified that carers needed to be able to understand complex medical knowledge about side-effects and symptoms. They also recognised that carers needed '*signposting*' to other resources that provide support, such as Macmillan Cancer Support.

> *'I think that the patients and carers need to be given permission, very much permission to ask questions, to ask stupid questions to access and I think that sometimes our approach precludes that from happening.'* (Senior Nurse, S2:8)

5.21 How Does the Service Currently Support Carers?

Provision of support to meet the needs of carers was ad-hoc, frequently dependent on whether individual practitioners recognised the carers' role and involved them when interacting with patients.

> *'I think sometimes it is dependent on the nurse and her skills. I don't think there are any very, I mean there are formal systems there like support groups like Macmillan, like CAB where they can get some of that kind of stuff but I don't think it is core to the patient pathway. I think it's one of those things that we do as an add on and if we want something from the patients like that's part of the discharge planning process then we might include them because it will be a demand on them but I can't, I wouldn't say it's really embedded.'* (Senior Nurse, S1:31)

There were no formal organisational strategies or resources in place to specifically support carers. Practitioners acknowledged that when support was provided it was usually reactive when a patient became very unwell or there was a crisis. Information obtained through monthly audits conducted by the units' staff of 'out of hour's calls' was reviewed. Half of all emergency telephone calls were from carers. Carers rang seeking advice for side-effects, such as, diarrhoea, vomiting and pyrexia.

> *'50% of phone calls to the chemotherapy telephone advice service were actually from carers, out of hours, this was out of hours that we looked at.'* (Senior Nurse, S2:8)

Some healthcare professionals encouraged carers to seek support from other sources such as Macmillan Cancer Support. Practitioners also recognised that it was easier to support carers at the end stages of a patient's disease, when the need for support was more obvious and they were able to refer carers to the hospice or palliative care services.

Even when there was a crisis concerning the patient, carers' needs could be overlooked. The quote below comes from an interview with a daughter. In this interview she described how at times she felt overwhelmed and had struggled to cope with the demands of her mother's illness. Although she perceived the nurses and service had supported her mother well throughout the treatment, no-one had identified she was struggling:

> *'I do sometimes and again it sounds selfish but sometimes when I say I think to myself when is this all going to end and I don't mean by my Mum dying or my sister-in-law dying but I just think when is this all going to end. When is this all going to stop? And you know.'*
> *RV: 'And has any of that ever been addressed by any of the healthcare professionals in the centre?'*
> *INTERVIEWEE: 'No.'* (Daughter, CB3)

5.22 Should the Support to Carers be Enhanced?

> *'We have a duty of care to the patient, but we also have a duty of care to their informal carers, because they're the ones that are going to take the patient home and look after them.'* (CNS S2:12)

Senior nurses, including CNSs and some doctors were able to articulate clearly the benefits of enhancing the support provided to carers. These healthcare professionals recognised that development of proactive strategies enabling carer involvement, could avoid emergency hospital admissions by preventing a crisis at home, enhance patient outcomes and increase patient and carer satisfaction with the service, thus reducing complaints. They also acknowledged that finding better methods to support carers could save healthcare professionals time and increase job satisfaction.

> *'I think just the needs of carers is second, is perceived as secondary which I don't necessarily agree with .. because I think that it doesn't, I think that doesn't make sense to me because if you, invested more time in their needs not only would it benefit the patient it would benefit us, because it would be a bit like having a really good student nurse, if you invest in a student nurse they're really good at looking after your patients but and then it makes it easier for you to carry on doing your job.'* (CNS S2:9)

Conversely, few CDU nurses could describe the benefits of providing support to carers.

Enabling self management for carers to care for patients at home was highlighed by some senior nurses (including CNSs) as being a necessary facilitative role nurses in particular needed to adopt.

> *INTERVIEWEE: 'I think in the Health Service we are less inclined to give over and let people get on with it themselves.'*
> *RV: 'Why is that important?'*
> *INTERVIEWEE: 'Because it means they are engaged. The relationship between the carer and the patient is what it's all about, it's their lives, it's not ours and I think we forget to whether we are a nurse or a CNS or a GP that we're only there for 5 minutes of these patients' lives. So give them skills. GP's do it quite successfully don't they; they're pop in, pop out, pop in, pop out.'* (Senior Nurse, S2:6)

Many healthcare professionals believed that communication between healthcare professionals, carers and patients and involvement of carers in the patient's care needed to be enhanced. However, most healthcare professionals, when asked what interventions could be developed, specifically to meet the needs of carers in the chemotherapy setting, struggled to answer.The reasons for this will be discussed in the next chapter. However, an interesting insight was offered by one CDU nurse when asked how support should be improved:

> *'It's kind of hearing it, acknowledging and sign posting. Some of it is just talking and listening and just listening sometimes because we don't always have the answers'* (CDU Nurse, S2:18)

5.23 Chapter Summary

The findings demonstrated that patients and carers felt, emotionally and cognitively, overwhelmed at the beginning of the patient's treatment and struggled to manage the amount of information that they received. In spite of patients receiving large volumes of both oral and written information about chemotherapy, family members reported they felt uncertain, not sure what to expect or what they should be doing. For patients and their relatives 'being safe' was closely entwined with 'feeling safe'. Patient participants felt safe in this study because the staff knew them. Patients felt they were well looked after by knowledgeable staff, while they were receiving chemotherapy in the CDU. Indeed all nursing staff who worked within the CDU had received education in chemotherapy.

Carers reported that they often had periods of feeling extremely uncertain about how to manage the adverse physical and emotional effects of chemotherapy or impact of treatment on everyday living when at home. Feelings of being unsafe and insecure were exacerbated, by receiving conflicting advice and information, not being clear about whom or whether they could, contact the service for advice. For carers, confidence and feeling safe did appear to increase over the period of the treatment trajectory, as they gained more experience (usually as a result of a problem or crisis) and had time to process both the diagnosis and the treatment plan. However, carers could be impeded in their role by both healthcare professionals and patients.

The findings have shown healthcare professionals, while seeming to understand the important roles and challenges carers have, frequently failed to acknowledge their value and give them the support and comprehensible information they need. Irrefutably carers and their needs were often ignored. However, healthcare professionals described, as will be shown in the next chapter, that supporting carers in this setting is complex. They experienced numerous challenges and barriers, which they perceived prevented them from preparing and supporting family and friends who support patients having chemotherapy.

Chapter 6 Fieldwork Findings: ‘The Barriers and Enablers to Supportive Care for Carers’

6.1 Introduction

In the previous chapter the experiences and needs of carers, from their perspectives and those of patients and healthcare professionals were presented. It was apparent that carers need support from healthcare professionals. Their needs were for role acknowledgement, receiving timely advice, information and support, to enable them to help patients manage the adverse effects of treatment (both physical and emotional). When interviewed, most practitioners could articulate carers’ numerous challenges but they acknowledged in practice the service rarely addressed carers’ needs, which generally remained unmet. This disparity between healthcare professionals’ knowledge and their behaviour needed to be explored.

Healthcare professionals described, in both formal and informal interviews, numerous challenges broadly arising from patients and/or carers, organisation and treatment, and health professional attributes. Practitioners perceived these challenges could create barriers, which they felt inhibited them from providing effective support and communicating with family and friends in this setting.

6.2 Challenges Created by Patients and their Families

6.2.1 Understanding Who Supports the Patient

Determining who provided support to the patient during chemotherapy and therefore, whom they should support, was frequently challenging for healthcare professionals. As identified in the previous chapter, many patients would attend appointments on their own. Alternatively, patients would appear with a number of people or have different companions on every visit. The interviewed healthcare professionals identified a lack of understanding of who the main support person was as a barrier. However, practitioners were rarely observed asking patients for an introduction or acknowledging companions when speaking to patients.

Healthcare professionals reported finding it confusing during the patient’s treatment, when it transpired the carer was not the person they initially thought. A doctor explained why on occasion it took time to understand who the patient’s key support person was:

> *'I think the huge challenge, say you take a patient and you go through the diagnostics into treatment is actually understanding what the family dynamics are and sometimes the people that initially appear with the patient aren't the right people, you know, either for the patient or because they can't handle it themselves and it sometimes takes a while A) for us to find out, but I think also sometimes it takes a while for the patient to find out, you know not exactly who their friends are but who is best able to support them in this sort of quite challenging situation.'* (Doctor, S1:25)

Some practitioners described how tensions could arise within families, when relatives vied to provide support for the patient. This then made it difficult for healthcare professionals to provide interventions encompassing the needs of the whole family.

Practitioners also found it difficult when patients' relatives or friends, while wishing to support the patient, were unable to. Reasons included the carer's poor physical or mental health, living too far away from the patient, competing commitments and low health literacy. Some healthcare professionals expressed concern about those patients who were isolated or unsupported at home. They felt that there was a more pressing need to develop strategies to identify and develop interventions for supporting these patients rather than developing interventions to support carers.

> *'It concerns me for the patients that haven't got any carers or anyone because it's those patients, because it isn't just about getting a temperature it's about living with cancer and living with chemotherapy and it doesn't just involve one person so they need to have a good support network around them and if they haven't then we need to look at ways how we can help them which can be quite challenging'* (Senior Nurse, S2:23)

6.2.2 Managing Difficult Family Dynamics

Understanding the subtleties of the patient's family and how they worked together was a major dilemma for practitioners.

> *'Well it's the family dynamics and I think that's quite difficult to work out… you know if you go and see a family therapist or whatever you'll have a session over three months to try and work out how your family dynamics work and we're having to take a patient*

> *through a crisis situation when they're, who knows what their relationship is like.'* (Doctor S1:24)

Managing challenges created by what was termed 'difficult family dynamics' or relationship problems between patients and their families, was stressful for healthcare professionals.

> *'Sometimes it could be quite intimidating if a husband and a wife are having a bit of a stand-off it might make the nurse a bit reticent about pursuing that in case it goes the wrong way.'* (CDU Nurse, S1:2)

Where tensions were evident in families the priority for healthcare professionals, was to support the patient. Some CNSs identified they encouraged patients to be open and seek support from families, but recognised this was not always possible. These difficult family dynamics were a real barrier, preventing healthcare professionals from providing supportive care to relatives and friends.

> *'If you double check with the patient they have an estranged relationship and it's no longer appropriate and they feel that they don't want you to communicate with certain members of the family, and of course you have to abide by their wishes. You may not agree with it as a healthcare professional, but ultimately you must support them in that decision.'* (CNS S2:12)

6.2.3 Managing Different Expectations

Healthcare professionals found managing patients' and carers' differing expectations of how the patient should be cared for challenging. Carers were more likely to have higher expectations than patients and make complaints if these expectations were not met. A CNS described how difficulties could also result from healthcare professionals' and service users' differing expectations of supportive care and tolerable side-effects.

> *What is acceptable side effects, what is acceptable kind of symptoms to live with at home is very different to what the carers or patients themselves feel is acceptable and I think these two expectations are very, very far apart.'* (CNS, S2:9)

Healthcare professionals reported patients and their relatives would arrive at appointments with different agendas and expectations about treatments. Situations, such as families advocating treatments when patients were reluctant to have it, were extremely difficult to manage.

> ‘*But very well informed carers are often coming in with lots of knowledge already, things that they’ve read about on the internet or things that they’ve found out and this can cause friction because sometimes the patients don’t, they’re like oh you know I told you to leave it and they’re like well I just want to ask about this or want to ask about that, so that can create barriers and tension in the room while you’re talking to them. You can see that the tension is occurring and especially with treatment choices as well.’* (CNS, S2:16)

Nurses in particular had difficulties in managing expectations and communicating with patients and their families who entertained unrealistic expectations of treatment efficacy. These usually occurred because from the onset the overall goal of treatment had not been clearly defined or understood by patients and their families.

Practitioners reported carers frequently wanted more information about treatment processes and prognosis than patients. They found balancing these disparities between the patients’ and families’ needs for information difficult. Conversely, one CNS described how patients were more accepting of their situation, than relatives.

> *And I’ve had times where I’ve had to take the carer out and leave the patient in the room with the consultant because the patient’s fine, got it, understands it, but the carer is not coping at all because they don’t want to imagine life without them.’* (CNS S2:11)

6.2.4 Managing Uncertainty

Previously it was identified that carers were frequently uncertain about the disease, treatment, and when and how to help the patient. Some healthcare professionals were aware of this uncertainty but were unsure how to intervene.

> *‘Because when you talk about cancer you talk about uncertainty, when does treatment start, how will it work, how will people be on it, how will it impact their lives, those are the kind of questions that we ask, get asked regularly by patients and carers and it’s always the one where you think well we have to wait and see, it’s an incomplete answer*

> *because they just want someone to tell them it's going to be alright and unfortunately it can't always be alright.'* (CNS S2:12)

Carers' constant anxiety resulting from feelings of uncertainty also created challenges for practitioners. Some healthcare professionals described these carers as '*needy*' or '*high maintenance'*, as they were more likely to make heavy demands on the service.

> *'Yes, well it's relatives for example that call in very frequently for patients that experience for example nausea and vomiting, that feel insecure and feel they need to either provide feedback several times a day or need reassurance several times a day. I think also situations where carers or relatives let's call them that, start to worry because they come across unfamiliar situations and then call for an ambulance where actually a phone call would have been sufficient to reassure them. I've come across that on occasions.'* (Doctor S1:30)

6.2.5 Independent Patients and Families

Healthcare professionals identified patients blocking family involvement in their treatment as a major barrier to providing support for carers. However, practitioners recognised some patients needed to maintain their independence. They believed patients wanted to try to keep control in a situation where they felt they had very little. As described by one senior nurse,

> *'I've seen this as well and it's purely personal, my view is I think it's their way of somehow controlling, having that kind of this is how I'm going to manage things but actually I think invariably over time it comes back and bites them.'* (Senior Nurse S1:31)

Some practitioners also thought patients wanted to protect their families. Patients sometimes came to the hospital alone, as they had a need to talk to healthcare professionals who understood their difficulties but weren't intimately involved. Healthcare professionals recognised this patient need. However, the quote below reveals how one nurse made assumptions about who the key providers of emotional support for patients were.

> *'There's only a little percentage I think that their informal carers are helping them like emotionally or psychologically. It's just that because when I ask them how are you, how*

> *are you coping at home, things like that, they tend to, I don't know their faces sort of change and it just sounds like they needed to just talk to somebody.'* (CDU Nurse S2:2)

Others recognised that patients were unwilling to bring their family members for fear they would share information about how the patient was really coping at home and side-effects they were experiencing. They acknowledged patients were not always as honest as they should be.

> *'I think the side effects, they possibly don't want to risk that I could be persuaded to stop treatment or reduce treatment, there is I think the perception that reduction in dose may be less efficacious and they feel that if they admit to side effects that they will receive less chemo and it won't be as effective.'* (Doctor S1:30)

Healthcare professionals identified carers could also be independent and preferred not to engage with the service, hence making it difficult for staff to intervene. Reasons included: the carer believing the service was for the patient, they had a stoical personality and preferred to get on and cope with it alone, or the carer being unable to recognise they needed support.

6.2.6 Everyone Is Different

Healthcare professionals acknowledged that every patient and carer was different and *'one size does not fit all'*. Patients had different reactions, both physical and emotional to treatments. Both patients and carers had diverse ways of coping and needs for support, making it difficult for healthcare professionals to identify how best to support carers, in the limited time they had with them. Practitioners recognised this also created a challenge in terms of meeting the study aims and developing suitable interventions for carers.

> *'It's going to be a tall order to tick everybody's box because people have different needs.'* (Senior Nurse S1:8)

6.2.7 The Ethical Challenges

Practitioners were also concerned that a conflict of ethical principles, such as the patient's right to autonomy, could arise if patients were unhappy about information being shared with carers. On occasions, addressing carers' information needs could place practitioners in a difficult position of colluding with the carer, or and/or breaching the patient's right to confidentiality.

Less experienced healthcare professionals were more likely to describe how these ethical and professional obligations created obstacles, which constrained them from providing support to carers.

> *'I suppose it comes down to relationships for different people isn't it really when they don't sort of talk to one another, then you get sort of the relative asking you questions and then you can't always answer them because of confidentiality and things like that…. It's very hard isn't it?'* (Support Worker S1:3)

Experienced healthcare professionals explained how they overcame these ethical obligations, either *'working around them'* or as one carer suggested they '*helpfully broke rules'*, or by having what they described as *'difficult conversations'* with patients and carers. Conversely, these experienced practitioners also recognised sharing more information with the carer than the patient was privy to could place carers in a difficult position.

> *'I think that can be quite challenging because then it potentially changes their behaviour towards the patient, the patient knows that something is up and it becomes quite unequal and I think that can be quite dangerous because then the patient potentially might have issues with the medical team or the nursing team that they've shared things, it becomes potentially quite unstable doesn't it?'* (CNS S2:10)

6.3 Organisational Challenges

The findings revealed that organisational factors created challenges, which could prevent healthcare professionals from providing supportive care to family and friends.

Practitioners perceived the treatment environment was not conducive to supporting carers. Healthcare professionals identified increased patient referrals for chemotherapy, due to the merger of the Trust and advancement in treatments, combined with reduced staffing levels, a major challenge. This made a significant impact on the availability of resources, time and space.

The Trust's financial difficulties had resulted in a number of services being either reduced or cut. The counselling and complimentary therapy services, for example, no longer existed. If they required psychological interventions from counsellors or psychotherapists, patients had to travel to other treatment centres, often at a considerable distance. These services had long waiting-lists. Some healthcare professionals were unaware that the counselling service was no longer available.

Healthcare professionals identified ensuring patients, rather than carers, had access to the available resources as a major challenge and priority.

> *'I have insufficient services to support my patients and I think they are the priority over the carer so if I don't have enough psychological support for patients there's no way I'm going to be able to support their carers. So I have to advise them to go and see their general practitioner. There is no psychologist available here.'* (Doctor S1:30)

Some healthcare professionals revealed they had significant difficulties identifying where to refer patients and families for support. However, there were available resources that could be accessed outside of the chemotherapy day units, such as the carer's GP and Citizen's Advice Bureau. Another example was the Macmillan Information Centre located at Site 3. Although services were predominately for patients, family members could access and obtain informational support from these facilities. However, few practitioners were aware of these services, or thought they could refer carers to them.

> *'They're not told that there are benefits there, from Macmillan. They're not told so I think that would be very good for patients, just to know who to go to for help. These people can help you with this; these people can help you with that. There's lot of support and help out there but nobody knows about it, it's all blurry.'* (CDU Nurse S2:18)

6.3.1 Who is Responsible for Supporting Carers?

Professional uncertainties and assumptions about roles created barriers preventing the provision of supportive care. While practitioners acknowledged it was everyone's role to support carers, many perceived CNSs had a greater responsibility than other health professional groups. CNSs were named as the patient's '*key-worker*', the person who had overall responsibility for being the first point of contact in the service and provider of support for patients and their families.

> *'I suppose my role is a standard CNS role, to be a professional friend to patients and carers, to be a point of contact between the multidisciplinary team, to ensure their pathway of care is adhered to and moves as appropriately as possible.'* (CNS S2:12)

Some healthcare professionals acknowledged different disease specific teams and CNSs worked very differently, which created gaps in the service.

> *'We have got plenty of cancer CNS's but they're not historically in the fashion of picking up their patients and seeing them and sorting them out [during chemotherapy] - it happens in a patchy way, there is some good practice and there's some very poor practice. So patients aren't necessarily seeing their key worker when they come through the organisation either and so there's a poor experience from that perspective as well.'* (Senior Nurse, S2:6)

During the fieldwork these inconsistencies in practice became very apparent because of how carers and CDU staff described their involvement with CNSs. Some carers had consistent support from the patient's CNS, others did not know who the CNS was or understood their role. Gaps in the service and professional tensions were created because different practitioners had different opinions on who should provide supportive care to patients and their families during the treatment phase.

> *'There's the expectation that that's the CNS's role. CNS's have the expectation that the chemotherapy staff will provide that bulk of support during that treatment period. So there's lack of clarity, lack of explicit expectations and it very much depends upon CNS's workload and their relationship with the chemotherapy unit as well, which isn't always there.'* (Senior Nurse S2:8)

Many of the interviewed practitioners, including doctors, stated CDU nurses' priority was ensuring that the patient received their treatments safely, in a system they felt was '*relentless*'. One senior nurse highlighted that patients frequently received contradictory messages about who they should contact for support.

> *'When patients start a course of chemotherapy it's made very clear to them who they need to contact at a point of a problem - it's not their key worker it's the chemotherapy staff.'* (Senior Nurse, S2:8)

Nurses described feeling frustrated because they perceived most doctors were disease or tumour focused, rather than patient focused.

> *'Healthcare professionals are barriers….. Because you know it all depends on how you communicate with people. Consultants and doctors will have a very different perspective to nurses that can be a barrier sometimes. They will look at the fact if we just treat it's going to make them better whereas we may think well her performance status is really bad, we're just going to make them worse. That can be quite a big barrier because there's conflict there before you've started; there just doesn't seem the time sometimes to focus on the whole person.'* (CDU Nurse S1:23)

The medical focus on disease was evident when observing the multi-disciplinary meetings (MDMs). While the purpose of the MDT is to collaboratively plan treatments and monitor patients' progress, rarely were patients' psycho-social issues or problems discussed. The patients' support at home was never disclosed. Indeed the CNS seldom contributed to the MDT meeting discussions. When CNSs were asked how these issues were brought to the attention of the medical team, they admitted that usually they raised concerns in one-to-ones with the consultant. Challenges that arose would be negotiated *'behind closed doors';* an example is when CNSs detected patients were really struggling to cope with treatment and it needed to be stopped.

Practitioners described feeling pulled between the need to support patients and their families effectively, and balancing the needs of the service and meeting targets.

> *'The management expectation to actually get the job done - there's a huge pressure there. And a huge pressure from the oncologists and from the haematologists to actually deliver on the wait times and things like that and so probably they've become conditioned to actually only ask what really needs to be asked rather than delve a bit more maybe.'* (Senior Nurse S2:23)

Others stated barriers existed because the organisation's financial incentive was to treat as many patients as possible. The Trust is paid for the number of patients it treats, not for the psycho-social support it provides.

> *'Such a cliché isn't it but it's just the Trust is financially challenged, supporting people doesn't necessarily, sounds awful, generate income.'* (CDU Nurse S1:2)

6.3.2 Organisational Guidelines

Practitioners' uncertainties about professional boundaries also created barriers. Posters, outlining the Trust's mission statement, were displayed throughout the hospital on Site 1 (but not Site 2). On this poster the Trust pledged *'that the best results come about when patients, their carers, relatives and staff are active partners in decision making and in the giving of treatment and care'* . Yet there was little guidance from the organisation for staff (that they were cognisant of) on how best to do this. Furthermore, healthcare professionals were aware that while there was an increasing policy drive for services to provide more support for carers, there was little clarification on what the professional expectations were.

6.3.3 Assessment and Documentation

Carers' needs were not formally assessed. Similarly patients' psycho-social needs were rarely systematically assessed. When patients' problems and needs were identified these were not consistently documented. This made it difficult for others, who would subsequently support the patient, to provide continuity of care and understand what had occurred previously. Assessment of patients by CDU nurses focused mainly on treatment toxicities.

During the fieldwork phase, a new national holistic needs assessment tool (the HNA) was launched by the National Cancer Action Team (NCAT 2011). This tool was to be used by CNSs and other key nursing staff with patients, from all tumour groups, at specific points in the disease trajectory (including treatment phase). Instigation of the HNA was a requirement for national peer review measures (quality assessment of the service). An aim of the HNA was to enable practitioners to more readily share important information about the patient, with others involved in their care, including the patients' GPs.

There was resistance from CNSs to this change in practice. Some believed it would interfere with the therapeutic relationships they had with patients. Having less formal interactions, '*chats*', they felt enabled them to identify patients' needs more readily. The nurses expressed concern this tool would result in another '*tick-box exercise'* not dissimilar to the chemotherapy toxicity scale currently used during treatment. CNSs also worried it would take up too much time, which they had so little of. Some CNSs and CDU staff did start using this tool but, as they identified, it did not acknowledge carers nor prompt the practitioner to ask who supported the patient at home.

6.3.4 Treatment Challenges

Healthcare professionals felt patients were happier having their treatment as an outpatient. However, the shift from in-patient to out-patient care had been a significant change in practice for some staff. This move had created unforeseen problems, which remained inadequately managed by the service.

> *'I think a lot of the problem is that chemotherapy is now an ambulatory delivery method - it relies upon the patient coming up the hospital and having their treatment as a day case and turning them round and sending them home..., it doesn't allow you the opportunity for a longer assessment which often you need for certain patients.'* (Senior Nurse S2:8)

Healthcare professionals reported treatments had also rapidly evolved, becoming more sophisticated and complex. Patients had chemotherapy for longer, and if one treatment failed they were usually offered another type or course of chemotherapy. Patients could receive multiple courses of treatment (described as lines) over many months or years. These rapid changes left practitioners struggling to keep their knowledge of drugs and side-effects up-to-date.

Staff reported that the potential for patients to experience severe adverse effects had increased. However, if treated promptly these effects are more likely to be effectively managed. Practitioners specified patients and their families must understand, how treatments work and are administered, the numerous side-effects that may occur, how side-effects are controlled, and the risks and consequences if side-effects were not quickly managed. Healthcare professionals described providing complex information to ensure patient safety in a very short time-span as challenging. The difficulties were compounded as information was provided at a time when patients and their families were still coming to terms with the diagnosis. As previously highlighted, patients sometimes preferred not to know very much about treatment and did not seek information.

> *'But someone needs to know about it because yes they have actively enrolled in a course of treatment and yet they don't want to know about the side effects, they don't want to know about the cancer, they don't want to talk about it.'* (Senior Nurse S2:8)

This was challenging for healthcare professionals, as they believed they had a responsibility to provide as much information as possible to ensure patients were safe. Some practitioners described needing to constantly reinforce the information to patients; however, this could create tensions, as described by one CNS below,

> *'He said you think I'm stupid you keep telling me the same thing, and I said no, I said even the most intelligent people, I said, if you're ill and you're worried and you're stressed and you know, thinking about tablets, you're only half listening to me so I'm just making sure that I've told you it all and give you the phone number, and he sort of oh yeah he said I hadn't thought of it like that.'* (CNS S1:4)

Practitioners were extremely aware that patients could become acutely unwell and die if some side-effects, such as neutropenic sepsis, were left untreated. Throughout the fieldwork healthcare professionals were rarely heard to explicitly inform patients or carers of this risk, practitioners avoided using the words, 'you could die'. Providing relevant information is further complicated for practitioners, because it is often difficult to predict how patients will physically respond and react to treatment. This was why, as some healthcare professionals explained, they gave information about every potential side-effect to patients. For most treatments the list of possible side-effects is extensive. One carer participant admitted she had taken very little interest in the information provided by healthcare professionals.

> *'Well it's a little bit like when you are given tablets by the doctor, if you read the leaflet in the packet you'd never take anything because they cover themselves for absolutely everything and if you look at it and you think oh God I'll get that, that, that and that, so yeah I was listening to what he was saying but you don't know until it's sort of actually done, you know what effects it is going to have on you.'* (Wife, CW7)

For healthcare professionals determining how much someone will be able to comprehend is difficult. Especially when they do not know the person and have limited time to explore what the individual understands.

> *'I mean if you are asking someone without any medical knowledge to become equipped with the right language and the right terminology and the understanding from the very minimal contact that they have with healthcare professionals then it's ludicrous to think*

that someone becomes equipped because they've been given a booklet on chemotherapy and a half hour session.' (Senior Nurse, S2:8)

6.4 Health Professional Attributes

Healthcare professionals perceived there were individual practitioner attributes which created barriers and prevented practitioners from communicating and providing support to carers.

6.4.1 Insights and Being Aware

When interviewed most healthcare professionals did acknowledge the important role family and friends assume providing vital support to patients. However, this awareness was rarely evident in practice. The pictures below in Figure 8 are of chairs at one of the CDU sites, the use of one was restricted, to be used only by nurses when administering chemotherapy, while the other was for visitors. The red comfortable chair is for nurses. When these pictures were presented to staff in workshops (to be discussed later in Chapter 7), they were very surprised and embarrassed. They had been completely unaware of the messages these chairs would send and how they could be perceived by visitors to be at the least, unwelcoming and uncomfortable. The patient chairs (one can be seen in the background of the picture on the right) however, were comfortable.

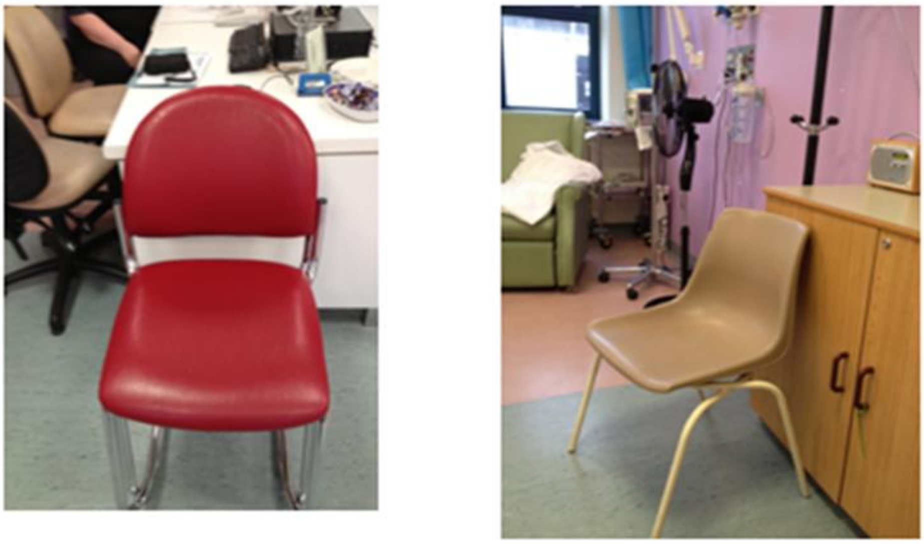


Figure 8: The 'Tale of Two Chairs'

In this study, CNSs who were interviewed, appeared to have a greater awareness of carers needs, than other health professional groups; they acknowledged this was because they had more time with patients and their carers than perhaps others did. However, while CNSs may have been aware of carers needs, some admitted possessing little knowledge of the chemotherapy treatment pathway. This was because they had been recruited into the role from a surgical rather than oncology nursing background.

> *'I think quite a few of our clinical nurse specialists don't have a very good understanding of chemotherapy so they tend to know all about the patient diagnosis etc. but will leave all the chemotherapy and side effects up to the nurses on the unit or on the wards and as a consequence I think there is probably quite a gap.'* (Senior Nurse S2:6)

Alternatively, some CDU nurses and one of the doctors described how they weren't clear what family and friends' actual needs were in this clinical setting and, therefore, found it difficult to know what support they should offer.

> *'I'm thinking of them [barriers] in order… there are many but I would say the first one is maybe not fully understanding what carers needs are because I'm not sure they've ever really been asked, so probably that.'* (CDU Nurse S1:2)

During the interviews, a number of healthcare professionals shared with me personal experiences of caring for a relative while they were receiving chemotherapy. Unsurprisingly, these practitioners seemingly had great insight into the challenges carers could experience. They acknowledged their experiences had influenced their practice.

> *'I think that was just a sea of change in terms of how I approach it. So I think I'm a better doctor for all of that.'* (Doctor S1:25)

6.4.2 Attitudes Toward and Beliefs about Carers

In interviews practitioners constantly reiterated the needs of patients, rather than focus on the needs of carers. Most stated '*their duty of care was to the patient'*.

> *'You may not necessarily be providing the carers with the support they need, but is that your job or is your job to focus on providing good quality care to patients, as many patients as you can, so that they are being treated for their disease. If the time and the resources aren't there what would you choose? Do you support more carers and treat fewer patients, or treat more patients and support less carers? It's a difficult choice, it is a difficult choice.'* (CDU Nurse S1:2)

Practitioners felt it was often easier, for reasons previously described, to provide support to patients, than to family caregivers.

> *'I still think there's a comfort in, you're very often comfortable with the patient but sometimes you are less comfortable dealing with the family,'* (Senior Nurse S1:31)

Healthcare professionals struggled with the term 'carer'. While they could easily define the term, as the key provider of support, who was either a relative or someone who had a close relationship with the patient, they felt ambivalent towards it. One doctor described how it was not a term he was familiar with until he met me. He thought it was a '*westernised healthcare* *label'*. He suggested that in other cultures, families assume a responsibility to care for their family member, and they were not given a name or role. Practitioners also suspected patients and their families could not relate to the term at this stage of the disease trajectory. They considered the term carer was more acceptable to family and friends at the palliative phase, when the patient was dying. Similarly, throughout the fieldwork, it was found that most relatives or friends did not view themselves as 'carers' and patients struggled with the notion they needed a 'carer'. As described by a patient's wife,

> *'Well I mean I find that quite difficult because you see well you know we got married and we said for better or worse, this is the worse, so it's wife rather than carer.'(*Wife, CW9)

The different attitudes of other healthcare professionals were a challenge for some practitioners, creating barriers to supporting families. One CDU nurse tearfully described having a different attitude than some of her colleagues caused difficulties for her. She felt her colleagues disapproved because she spent time with patients and their families, talking with them, rather than just focusing on administering the drugs.

> *INTERVIEWEE: 'Some people are very, very quick and they don't maybe chat with them like I do or if they do feel a problem they just ….Back off'*
> *RV: 'And what do they perceive their job do you think to be then?'*
> *INTERVIEWEE: 'Just issuing, I think, it's very hard for me to say anything.'* (CDU Nurse S2:5)

Some nurses identified they did not know how to approach a patient's family or friends to offer support. Or indeed felt it was their role.

> *'It's very difficult to go about talking to not one of our patients. If it's a relative it's a bit difficult to talk to them and ask them about things like that because it's very private isn't it? I would say I'm not the best person to ask them about things like that, I don't know how to approach them.'* (CDU Nurse S2:2)

6.4.3 The Emotional Work

To encourage practitioners to talk, many of the interviews were started by asking whether they liked their work and if so for what reason. Their responses provided interesting and unexpected insights. All healthcare professionals acknowledged gaining great personal satisfaction from their work. Many used strong, emotionally laden words to express how they felt,

> *'I love it. I love it. Well I sort of think I always sort of think of it as a job where we don't cause, we're not responsible for any part of their cance,r we're just somebody that can help them once they've got it. We're a good thing in a bad.' (*CNS S2:9)

Healthcare professionals reported their work constantly tested and provided them with new opportunities to learn. Nurses, but especially the CNSs, aspired to have sustained and meaningful relationships with patients and gained great satisfaction when this was achieved.

> *'The more I worked with patients the more I'd say that that relationship was extremely important to the patient and it became more apparent over time that relationship was very key to them feeling safe and secure and satisfied with the care that they got and because they fed that back it became more rewarding and the desire to improve whatever I did came from that kind of relationship, wanting to help people more and be a good nurse I suppose.'* (Senior Nurse S2:8)

Conversely, dissatisfaction with their roles derived from managing the politics of the organisation and difficult members of the MDT. Healthcare professionals reported they frequently felt undervalued by the organisation. Practitioners also admitted feeling constantly '*guilty*' and '*frustrated*'. These feelings arose from their perceptions of being unable to provide consistent, effective care and time to patients and their families. One nurse described feeling so discouraged because she would '*never be able to do enough'.*

> *'I feel as though, I think that's why I feel physically and emotionally exhausted because we're trying to hold this system up but I feel it's quite threadbare some days and I think it's, you know, I think we're just holding it up sometimes, just getting through safely and try to hide the imperfections which are definitely there.*' (CDU Nurse S2:5)

Practitioners found negotiating the highly technical and skilled aspects of their roles, with the emotional work extremely challenging.

> *'Because it can be an ever expanding, you can expand into so many, like opening Pandora 's Box, when the prime role is safe administration of treatment and keeping the patient safe and to get through the treatment,'* (CNS S1:4)

Maintaining patients and their families' hopes, while being honest about the efficacy of treatment, was difficult for healthcare professionals. Practitioners admitted they often avoided talking about the possibility of dying with patients and their families, for fear of creating more distress.

> *'I think there are, for patients who are dying, there's certainly a period of time where it's the elephant in the room until somebody decides to openly talk about the process of dying which is usually facilitated by Macmillan nurses.'* (Doctor S1:30)

During the interviews some nurses admitted they personally experienced distress or fear when confronted with strong emotions.

> *' When you're out on the shop front as the saying goes it can be really unnerving and it can be really scary and you can feel like bursting into tears at times'(*CNS S2:11)

Some practitioners admitted they felt '*helpless*', as they perceived they had limited skills to manage this difficult aspect of their work.

> *'Certainly working clinically sometimes you are so focused on getting things done to the patient there's almost like a sigh of relief when you've looked after the patient to then worry about the family, and sometimes it's almost like another ask that you've got to do or something that you avoid for whatever reason, capacity, skills or whatever.'* (Senior Nurse S1:31)

Instead they would use avoidance strategies and distance themselves from carers by focusing on the patient and/or the task they needed to perform. Practitioners acknowledged they had little resources and time to address carers' concerns toward the disease and treatment. They also feared talking with carers about their concerns would trigger distress in the carer and/or patient, so consequently they avoided engaging with carers.

During the fieldwork, healthcare professionals were frequently heard using the analogy '*it's like opening a can of worms*', when describing why it was sometimes difficult for them to address patients' and their families' emotional needs and provide support. As described by one senior nurse

> *'I have to admit sometimes myself I didn't want to do it because it sort of opened this can of worms up and you didn't have time to address it and sometimes the same problems arose with each time and you got a bit weary of addressing what seemed to be an insoluble problem.'* (Senior Nurse S2:8)

Nurses also described how they frequently felt the need to 'act' in their role by hiding their own emotions from patients and visitors,

> *'I work in a fish bowl...Where every single minute thing is picked up, whether I'm on the phone telling someone off in stores because they haven't delivered something I requested a week ago or whether I'm chatting to a patient on the phone about a problem.. Instantly - what's wrong? Why are you not smiling? So you do feel a bit like you're on a parade all the time and I guess the patients must feel like that as well, must put my smiley grin and bear it, face on…. It is hard work.'* (CDU Nurse S2:18)

The emotional work undertaken by practitioners when supporting patients and their families was not recognised nor valued by the organisation. Furthermore, healthcare professionals constantly shared with me how '*uncertain*' and '*unsafe*' they felt, due to the instability of their work environment. As a result of financial difficulties and merger of the Trust, they were uncertain whether they would have a job and who would be managing them.

> *'I felt I had job security at one time but I don't feel secure anymore.'*(*CDU Nurse S2:5)*

There were no formal mechanisms, such as clinical supervision, to provide consistent support and develop every member of staff in these aspects of their work. However, I was aware when participating in the work of the units that staff were, on the whole, extremely supportive of each other.

> *'We all support each other and as I say when we get upset we, you can't cry in front of patients obviously but you can feel it, there's a feel that you just feel that if you've had a*

> *crap day you might not always want to talk about it but your colleagues are there to support you.'* (CDU Nurse S1:23)

To summarise, it is clear from these findings that healthcare professionals' experience numerous challenges. These often prevent them from providing support and communicating effectively with family caregivers. Conversely, healthcare professionals did recognise, the need for and benefits of enhancing support for carers; and nearly all acknowledged the importance of undertaking research in this area. However, when practitioners were asked in the interviews what type of interventions should be developed specifically to meet carers' needs, they struggled to answer.

> *'I don't actually I think you will never get a complete answer from anyone because we all have varying opinions and to a greater or lesser extent we recognise how important carers are, and to a greater or lesser extent carers will recognise how important they are in helping their loved ones or their friends or colleagues through this. And there is no right or wrong in this situation, you have a set of circumstances, you have a set of resources, and often there will be a dichotomy between the two and it's just about trying to manage someone's pathway with the resources you have, and empowering people to ask you for help.'* (CNS S2:12)

6.4.4 Intervening in an Ideal World?

As more interviews were conducted, questions evolved and practitioners were encouraged to think creatively about possible interventions. They were asked how they would in an ideal world, enhance the support provided to carers. Unsurprisingly having more time, resources, staff and improved clinical environments were frequent responses. One CDU nurse suggested having someone whose primary role would be supporting family and friends, '*a health professional just for carers'* (S2:2).

Some practitioners identified that in an 'ideal world', healthcare professionals could potentially conduct one-on-one pre-chemotherapy assessment sessions with carers and provide information tailored to their needs. Education provided in these sessions would provide carers with the necessary skills required to support patients at home. However, they acknowledged pre-chemotherapy sessions had not as yet been effectively managed for patients and weren't convinced in reality this would be feasible.

Another frequent suggestion offered by healthcare professionals was establishing support groups for carers. Conversely when interviewed, relatives were not enthusiastic about coming to the hospital for a '*carers support group'*. Furthermore, while I was data collecting at Site 2, the local hospice held a workshop for carers. Although well advertised, no-one attended. I talked at length, with the workshop facilitators about possible reasons for this. As identified in the previous chapter, the facilitators felt patients and carers probably viewed the organisation as '*the patient's place'*. Carers did not want to come to the hospital for their support needs. The hospice facilitators also suggested carers were perhaps '*too busy caring'* to attend or as yet did not view themselves as carers.

One CNS, suggested that *'support groups are like marmite you either love them, or hate them*' (S2:11). While another nurse described how protecting patient confidentiality in these groups could potentially be difficult. Rather than a support group, a chemotherapy educational session clinic, was proposed by one senior nurse and a support workeras an alternative method for preparing and supporting patients and carers. Here peer support could be also be encouraged.

> *'I don't know, it's like having a little teaching session isn't it, you know, that's what you need isn't it, it would be helpful. I think it would be because as I say when you've not come across it before it is a lot to take on, I think anyway.'* (Support Worker S1:3)

6.5 The Enablers: What Would Help?

While practitioners found it difficult to identify a specific intervention for carers, practitioners, (mostly CNSs and senior nurses) offered different approaches and strategies for working with and providing support for carers. These strategies they either used currently or perceived would be helpful to do so.

6.5.1 A Shared Understanding

Each MDT member having an understanding and respecting the contribution of other members of the team was deemed vital. One senior nurse outlined the necessity of nurses valuing their own contributions in order to be valued by others. Furthermore, support provided to carers would be enhanced if all those working in the units had a shared philosophy, which emphasised holistic patient-centred care.

> *'And believing in a shared ethos - we need to have a shared ethos for the unit and what are we here for, what are we doing and how do we involve, you know there's a carer element there and actually recognising that and not just paying lip service to it.' (Senior Nurse,* S2:23)

> *'I think it would just be really nice if, and it isn't a reflection on the doctors it really isn't because it does seem as if I'm bashing them a little bit but it isn't, but if sometimes they just stood back a little bit and just, and they do in the main we have very good relationships but respected the fact that that person is part of, it's not a tumour, it's a person, they've got a family'* (CDU Nurse S1:23)

Having organisation and/or professional guidelines, which outlined the parameters of working with patients' families, was also important for some healthcare professionals. These would provide a useful benchmark for the service and staff to aim towards.

> *'I mean we have guidelines on management, as in practical management, chemotherapy, radiotherapy, etc. and it would be useful to have some guidance on how to manage the carers….. actually I was going to point out is that we do have Registrars that come and go a lot so having some formal guidelines for them would be really useful as well.'* (Doctor S1:24)

Two senior nurses suggested that a shared understanding within the service could only happen if there was someone willing and able to lead on this aspect of the service. Having a leader who valued this aspect of supportive care was deemed imperative.

> *'But it was priorities, it was about how the culture of the organisation or how the culture of the unit runs as well and it's always about the leadership because if you've got a chemotherapy unit where your lead nurse is empathetic, really quite skilled at gathering all that sort of little bits in for the patients then everyone else will follow - that's the role modelling.'* (Senior Nurse S2:23)

6.5.2 Identifying Who Supports the Patient

While some practitioners always encouraged patients to bring their carers along to the main appointments, some did not or assumed that others had. Therefore, shared strategies that implicitly identified and acknowledged the person's key support at home was thought to be vital.

The first key interaction with the service was when patients attended the consultation for their diagnosis. Practitioners suggested it is at this appointment patients should be asked to identify who supports them at home, and whether it is acceptable for healthcare professionals to discuss the patient's care with this person.

> *'I think involving them as much as possible at the pre-treatment stage is really important and trying to give them an awareness of what to look out for and what emergency things to look out for, what triggers to ring us but also being really available and really accessible I think is one of the most important things.'* (CNS S2:10)

Patients were sometimes unwilling to bring someone with them. Therefore, some practitioners suggested the service needed to be far more direct with patients, clearly explaining the necessity of a support person involved from the start.

> *'I've actually had to say well I think this is the time when they do need to come, you do need to ask them for help and get them to think about that and they've actually gone away and done it and it's been quite fruitful - we've had daughters or sons coming to the clinic, listening to what's going on and having a much better idea of what's going on, but also taking some responsibility for their relative.'* (Senior Nurse S2:8)

It was identified that nurses should conduct a thorough holistic needs assessment (HNA, NCAT 2011) with the patient prior to treatment starting. Within this assessment, the CNS or CDU nurse would formally identify, where possible, the patient's key support person. Documenting this information, so knowledge about patients and their families could be shared with other members of the team, to be reviewed throughout treatment, was thought to be vital.

Two CNSs described how they asked patients to nominate one member of the family to act as the link between the hospital and home, especially if the patient had a large family.

> *'What you say to them is look guys I'm more than happy to talk through any issues that you've got but if it's specific things attaining to whoever the patient might be, Dad,*

> *brother or whatever then you say look I would rather talk to one person at a time and then you can cascade that information down and do it that way because otherwise you are on the phone to everyone and you can, there's only certain amounts of times you can have the same conversation.'* (CNS S2:11)

6.5.3 Giving Permission and Guidance

Giving permission to relatives or friends, to encourage involvement in the patient's care, was identified as important.

> *'You educate the patient and the carer together and start off the process together so they know they have a huge role to play and that they are valuable but they will at some stage need some help, because no man is an island, and that it's OK to ask for help, it's not a negative to say I cannot cope, I need help to cope with x, y and z, it's a positive empowering thing.'* (CNS S2:12)

Some healthcare professionals highlighted the importance of providing clear directions to patients and their families about how the support person could help. Practitioners described how they negotiated roles with both parties. The quote below is from a dietician, who regularly met with patients and their families who were in conflict or distressed. Preparing food and encouraging patients to eat is something family caregivers perceive they can easily do. However, when the patient refuses the offered food (anorexia is a common side-effect), it can create a struggle between the two. The patient's diet and whether they were eating well was a major cause of concern and anxiety for carers.

> *'Help to clarify what the actual aim is and maybe like designate responsibilities, allow the patient to be responsible for what they are taking in and have that control and the carer just taking on the role of just preparing a food and providing it for the patient. I think that has proved in quite a few circumstances to really reduce the amount of anxiety for both.'* (Dietician S2:26)

Staff thought using proactive interventions such as telephoning patients at key points and providing guidance to patients and their carers when they were most at risk would be a useful strategy to have in place,

> *‘Giving permission, but equally almost like putting something in the system that encourages that kind of well actually you are going to get help now rather than having to wait for you to tell us well actually this is, we know instinctively people go under here so this is when we are going to put some kind of proactive intervention in rather than you to have the screaming ab dabs at 3 o’clock in the morning.’* (Senior Nurse S1:31)

Signposting patients and their families to other supportive resources outside of the organisation were deemed vital. However, providing this guidance required the practitioner to have an understanding of the available resources.

> *‘Do onward referrals if they think someone needs to see a dietician or they think that a relative or friend wants to access the counselling service then we can signpost them, or things like signpost them to Macmillan for benefits or money advice.’* (CNS S2:10)

Some nurses acknowledged that before referring on to others it was important for staff to recognise maybe all that carers needed was an opportunity to talk and share their concerns with a professional.

6.5.4 ‘Using What We Have More Effectively’

During the fieldwork, I assessed what information resources and leaflets were available, in the units, for patients and their families. There were numerous leaflets (mostly published by Macmillan) and some DVDs available. Some provided generic information for carers of those living with cancer, and others described chemotherapy treatments. Leaflets were placed on shelves in the waiting rooms and were often given to patients at the pre-chemotherapy consultation. A senior nurse acknowledged, while there were support mechanisms in place for carers, it would be useful to have different approaches for using them. One CDU nurse described how she used the information booklets from Macmillan as an opportunity to covertly engage with carers.

> *‘I just say oh you* [the carer] *might find this useful and normally when they see the front they’re like oh OK and then sort of the patient will go oh that’s good, yes have a read of that, so that’s normally kind of the back way into supporting them I suppose by giving them a tool to make some phone calls.’* (CDU Nurse S2:18)

A carer participant described, having a resource just for carers would be helpful. As this would acknowledge that carers had permission to contact the service and give a clear message to patients that this was an expectation, carers were considered part of the patients' team.

> *'If they, if the carers actually had a book that they could class as theirs that had all the contact numbers and what have you….But I've had to like thumb through stuff and what have you and jot things down and but if I had my own and mum would accept that that's all part of the package - you have your own.'* (Daughter, CW8)

6.5.5 Enhancing Teamwork

In the previous section, it was identified that while everyone had a responsibility to support patients' families and friends, the CNSs had a key role. Teams worked differently across the sites and some were considered more effective than others. Some practitioners recognised enhancing communication and identifying strategies for more effective teamwork between the CDU and CNSs was imperative. Below is a quote from a CDU nurse that provides an example of how one CNS team worked with the nurses in one of the CDUs. She believed all teams should adopt this approach, as it would enhance patients' and families' preparation for treatment and improve on-going support.

> *'The CNS will bring them to the chemo unit, they will introduce them when they're setting up the treatment and then they will visit them, not every time but when they start their treatment they try to visit them and say right are you OK, yeah, yeah, and there's like a handover, the team will look after you and if there's a problem along the way we will call that person. Equally I've seen when that person has then gone along and had problems at home, we've dealt with the initial thing but then we'd let the key worker know and they followed it up because the relative, wasn't coping particularly well so I spoke to the key worker and said look I sense an air of tension, and she rang that relative and said are you OK, what help do you need and followed that right through.'* (CDU Nurse S1:2)

6.5.6 'More Tools for our Tool Box'

Nearly all the practitioners acknowledged they had received little preparation or professional development to help them manage the complexities of working with carers. One senior nurse (S2:8) suggested what healthcare professionals needed was '*more tools for our tool box*'; by having opportunities to develop a range of interpersonal skills and flexible strategies to manage the gamut of different situations that could arise with patients' families. Study days or workshops that focused on enhancing '*carer awareness*' and skills for managing family dynamics was suggested by a number of practitioners.

> *'Like a carers support study day containing information on how we go about, ideally, supporting the carer and places that we could refer to or how to go about doing things.'* (CNS S2:24)

A recurrent theme, throughout the interviews with healthcare professionals, was the importance of the practitioner actively engaging with the patient's support person when opportunities arose. Healthcare professionals believed that being able to engage effectively depended on the practitioner having good interpersonal and communication skills. While there had been some recent opportunities for senior staff to attend an advanced two or three day communications skills course, hosted by Connected, a subsidiary of the National Cancer Action Team (NCAT, 2013), it was acknowledged everyone would benefit from having more communication skills training.

> *'I just think everyone should go on a counselling or a communication course….Because we just need to be able to, communication is like 95% of my job. 5% is giving the treatment, the rest was all about talking to people, understanding people, understanding how they're feeling, having empathy.'* (CDU Nurse S2:18)

Practitioners identified specific communication skills which they either used, or viewed as important to develop. These included active listening, techniques for seeking information, negotiation, conflict management and skills for managing difficult conversations/emotions. One CDU nurse suggested communication skills for fostering a speedy rapport with people were vital.

> *'I think it's very useful also in an environment where in a high turnover chemotherapy unit where relationships have to be built very quickly and are absolutely fundamental to making things work, you haven't got the luxury of taking time to do that, so I think that's really good training for people in that environment.'* (CDU Nurse S1:2)

As previously identified the pre-chemotherapy consultation, usually conducted by CDU nurses, was the patient's initial induction to the service and treatment. Few nursing staff had received training for managing consultations, a relatively new nursing role. Practitioners suggested it would be useful to have a universally agreed framework and approach for conducting these meetings.

> *'We were talking about how you present the idea of a triage emergency card, what, how do you tell people to get a thermometer, how do you tell them to ring up, what do you say, do you say if you don't ring up you are going to get really sick, you know, potentially you could die. Every single person says it differently.'* (CNS S2:10)

Carers and patients frequently struggled to manage the overwhelming amount of information they received. Few carer and patient participants remembered what they had been told at the pre-chemotherapy consultation. Staff acknowledged they needed more effective methods and skills for delivering information,

> *'How best to get the information across in a way that they are going to remember because a huge amount of information there but trying to communicate that is the challenge isn't it, especially for nurses that have only been there a few months that might not have ever done it.'* (CNS S1:4)

6.5.7 Opportunities to Learn from Each Other

Some nurses admitted they had mostly learnt their communication skills through *'experience and making mistakes'*. They suggested creating opportunities to learn from each other would be useful. While others acknowledged learning from role models and understanding what strategies others use to engage with and support carers was vital. It is important to note, it was often difficult for practitioners to observe pre-chemotherapy consultations, as these and other key meetings happened behind closed doors. Consequently, there were limited opportunities for nurses to observe and learn from role-models. Conducting these consultations in pairs, and/or 'buddying up' a CNS with a CDU nurse, was identified by one CNS as a valuable strategy.

> *'I think in chemotherapy you do tend to be, you're not a lone worker but to some extent you are because you're quite focused on your patient, you don't have things like handovers which you would on a ward ...Or opportunities to debrief... Yeah and what happened in there….. You don't get that in the treatment suite environment so much or*

> *an out-patient environment so having that kind of support, peer support is really important and having a chance to compare how you do things.'* (CNS S2:10)

6.5.8 Being Brave

For practitioners to 'open the can of worms' in other words, engage with and communicate openly to patients' family and friends, required them to be brave and have confidence they could manage, within time constraints, whatever issues arose.

> *'I think sometimes that they don't realise how much hard work it's going to be [for carers] and how much they're taking on and sometimes I think we aren't very good at having those sorts of conversations with them and I think sometimes that we need to be braver and step forward and say right after it's sunk in what's happening.'* (CNS S2:11)

While another senior nurse suggested that to manage potentially difficult communication interactions between patients and carers required practitioners to:

> *'So it's about, I think it's about being honest, honest and open….Yeah it's about that kind of going in there and about well actually I've upset the patient and I've made them cry and then being comfortable with that.'* (Senior Nurse S1:31)

6.5.9 Time to Think

During the fieldwork, I became even more mindful of the very difficult job healthcare professionals do all day, every day, with very little time to think or reflect on what they were doing. Consequently they responded to events reactively rather than proactively. Practitioners acknowledged they needed time to think, as individuals and together.

> *'I think really what nurses need to do they need to try and be a bit objective and stand back and look at what they're doing and review their practice. I think chemotherapy nurses are so involved in the delivery of the treatment that perhaps not enough time is given to the development of that area of practice, if you see what I mean.'* (Senior Nurse S2:23)

6.6 An Overview of the Barriers and Enablers As Identified by Healthcare Professionals

The table below provides an overview of potential strategies proposed by healthcare professionals in both informal and formal interviews. They perceived these strategies would enable practitioners to enhance the support they and the service provided to carers. While nearly all the healthcare professionals who were interviewed believed that the service did have a responsibility to support carers, in the chemotherapy setting supportive care for patients and carers was predominately thought to be a nursing domain. However, the nurses reported frustrations and tensions between the need to deliver an efficient, safe service with providing supportive, person-centred care in this extremely busy clinical environment. Interventions were required, which would enable nurses to lead on this aspect of supportive care and enhance the preparation and support received by both patients and carers.

Table 20: A Summary of the Barriers and Enablers as identified by Healthcare Professionals

Challenges/Barriers	**What was Needed?**	**How? Potential, Useful Strategies Identified by Healthcare Professionals**
Organisation		
Different perspectives of healthcare professionals	Having a shared philosophy	• Leadership that endorses the ethos. • Establishing guidelines and clinical protocols. • Defining the parameters.
Different attitudes towards carers and limited understanding of their roles	Shared Understanding/ Philosophy	• Recognising carers as a resource. • Awareness of carers' needs. • Recognising each other's contributions. • Awareness of responsibilities.
Limited time and resources	*'Utilising what we have more effectively '*	• Knowing what resources are available. • Understanding and valuing each other's contribution.

Challenges/Barriers	What was Needed?	How? Potential, Useful Strategies Identified by Healthcare Professionals
		• Enhanced teamwork. • Clarification of preparatory information sessions. • Using the information resources more effectively .
Gaps in continuity of care	Improved continuity of care	• Better methods for documenting and sharing information. • Guidelines. • Proactive telephone calls to carers (especially if they are unable to attend meetings). • Proactive telephone calls after administration of treatment to those patients identified as at risk either because: a. They do not have support at home b. Patients and carers appear to be struggling c. They are identified as at risk of neutropenic sepsis or other serious complications
Gaps in service and care provision	Enhanced teamwork	• Handover at the beginning of the shift (CDU nurses). • Handover from CNS to CDU. • CNSs raising psychosocial issues in MDT meetings. • Handover to CNS from CDU.
	Leadership	• To establish a shared ethos. • Lead on changing practice. • Provide support to less experienced staff.
	Formal holistic needs assessment (HNA, NCAT, 2011) of patients to include assessment of the	• At the beginning of treatment. • Reviewed during treatment. • Shared with all members of the team.

Challenges/Barriers	What was Needed?	How? Potential, Useful Strategies Identified by Healthcare Professionals
	availability of a carer and their needs	
Carer/Patient Challenges		
The terminology used e.g. 'Carers', is not readily recognised or accepted and difficult for healthcare professionals to use	Explanations of terms	• Sensitive discussions with patients. • Use other ways to explain the role e.g. support person.
Carers do not know what is expected of them	Identification of the patient's support person	• Assess at diagnosis. • Assess again at pre-chemotherapy assessment/information sessions. • Acknowledge and include carers in consultations. • Give carers permission to be involved and contact the service (with the patient's consent).
The isolated patient	An awareness that these patients may need greater support from the service and other sources	• Explore with the patient if there is anyone they could call upon to support them at this time. • If the patient is isolated and has no-one to support them, the MDT team and CDU should be made aware.
The independent patient	Acknowledgement of the carer role but not to the detriment of the patient's right to autonomy	• To explain to patients that the service recommends the patient has someone to help during chemotherapy. However, it must also be recognised that some patients may be isolated and have no-one who could fulfil that role. • Identify with the patient what support they may need at home and who could potentially help them.

Challenges/Barriers	What was Needed?	How? Potential, Useful Strategies Identified by Healthcare Professionals
		• Outline that the service welcomes and acknowledges carers. • Provide patients with an explanation of the importance of the role. • If patients are resistant to family or friends being involved, explore why this is the case. • Respect and document the patient's wishes and social circumstances.
Different expectations	Explanation of what to expect from the service, (define the parameters)	• Explanation that healthcare professionals, patients and families are working together as a 'we'. • Clarify the service's expectations that patients will bring their key supporter with them to the main appointments. ○ When their key supporter is unable to attend practitioners could proactively seek their involvement e.g. telephone them after the appointment. • The carer is welcomed and encouraged to contact the service. • Contact details are provided.. • Help patients and carers identify other resources which can provide support.
Managing patient and carer uncertainty	Having honest dialogue at timely points Better methods for providing information	• Awareness of carers' needs. • Skills for managing difficult conversations. • Exploring other methods of providing information.
The pre-chemotherapy consultation ('it's not a	A shared understanding of the purpose, content and process of	• Multidisciplinary work to determine the purpose of the consultations.

Challenges/Barriers	What was Needed?	How? Potential, Useful Strategies Identified by Healthcare Professionals
chat') and everyone does it differently	these consultations	• Developing consultation skills of all staff. • Recognising that the information process is on-going throughout treatment.
Limited available resources or underutilised resources	Signposting carers to other resources	• Awareness that carers may need support. • Recognising that listening to the carers' concerns may be all that is required. • All staff have a clear understanding of what resources are available, for example: ○ Citizens Advice Bureau ○ Counselling ○ Chaplain ○ Macmillan information centre ○ GPs
Professional Attributes		
Lack of awareness	All staff have an awareness of carers' needs	• Raise the profile of carers across the service. • Leadership • Clear guidance from professional bodies.
Lack of knowledge and confidence in skills	*'More tools for the tool-box'* Continued professional development • Having time to stand back, for	• Developing communication, consultation and interpersonal skills: ○ Listening ○ Seeking and delivering information ○ Empathy ○ Negotiation

Challenges/Barriers	What was Needed?	How? Potential, Useful Strategies Identified by Healthcare Professionals
	thinking creatively and sharing strategies as a team - Opportunities to learn from role models	○ Managing difficult emotions ○ Developing rapid rapport ○ Telephone triage ○ Advanced assessment ○ Assertiveness ○ Encouraging patients and carers to self-manage
Anxiety about getting it wrong. Fears of *'It is like opening Pandora's box'* or *'opening the can of worms'*	Courage and Confidence	- Being able to try strategies out. - Gaining '*more tools for the toolbox'.* - Being able to readily access support from peers and role-models. ○ Protected and supported time out for staff. ○ Pairing up in consultations e.g. CNSs and CDU staff.
The need to protect the patients' rights to confidentiality	All practitioners understand the legal and professional expectations of confidentiality in relation to carers	- Clear guidance from professional bodies and the service outlining how to manage the ethical dilemmas, which could result from supporting carers.
Practitioners feeling guilty and frustrated.	Managing unrealistic expectations Increased self-efficacy	- Receiving positive feedback and a sense of being valued by the service. - Understanding when good is good enough. - The parameters for working with carers are defined (by the service and the profession).

6.7 Chapter Summary

The findings, reported in Chapter 5, revealed that healthcare professionals do perceive they have a responsibility towards supporting carers' needs. However, it was found that carers' needs remain largely ignored and unmet. In the review of reviews (Chapter 2) it was found that research investigating the needs of and interventions for carers has paid scant attention to healthcare professionals' perceptions of working with carers. In the methodology chapter (Chapter 3) it was argued that it is vital to understand healthcare professionals' perspectives of the factors, which may prevent implementation of change in the clinical setting.

In this chapter, numerous barriers have been presented, which healthcare professionals perceive prevent them from engaging with and supporting carers of chemotherapy patients. These barriers are created by the patient and carer (knowledge, emotions, and attitudes), the organisation and practice setting (resources, time pressures, lack of guidelines, unclear supportive care pathways, environmental constraints), the multi-disciplinary team and the individual attributes of the practitioners (emotions, attitudes, carer awareness, knowledge, shared understanding and skills).

Unquestionably, many of the barriers identified in this chapter could also impede the implementation of an intervention aimed at supporting carers. However, when developing complex interventions it is also equally important to identify what could enable healthcare professionals to change their practice and improve the support to carers, in a way that is feasible and acceptable to healthcare professionals. This chapter has presented healthcare professionals' perspectives of practical, feasible strategies and skills that could help practitioners and the service to improve the support provided to carers.

Chapter 7 The Modelling Phase: ‘We Can Try Things Out’

7.1 Introduction

The modelling phase of this study sought to identify and develop, with healthcare professionals and carers, components of an intervention to enable healthcare professionals to prepare carers for, and sustain them in their care-giving role when supporting people receiving chemotherapy. A further objective was to assess the feasibility and acceptability of the developed intervention/s components. The final objective of this study was to identify the training and support required by healthcare professionals to engage with, prepare and support carers.

To meet the objectives of this modelling phase, an action research approach was adopted. This phase began in August 2012 with a series of meetings with healthcare professionals working at the research site and further meetings with project advisors. Two workshops were organised, one for each of the CDUs (research sites). Here the pre-clinical phase fieldwork findings, generated through participatory observation and interviews, were presented.

Following the workshops the practitioners, with input from the carer advisory group, started developing tools, this formed components of a complex intervention. A spiralling process of planning, acting, observing and reflecting ensued. My key role within this phase was that of a facilitator, who as Dickens and Watkins (1999, p. 132) suggest *‘is needed to unfreeze the group dynamics so that participants can proceed to make changes.’* However, this phase required a major transition from a position where the research was primarily led by me to one where the participants had far more control. There were also numerous ‘spin-off’ actions.

Throughout the modelling phase, field notes and a reflective diary were maintained. A record of all meetings and correspondence was kept, for example, email and telephone conversations.

This chapter will present the participatory meetings, subsequent actions and findings from the modelling phase of this study, initially conducted with participants from the research site (Table 21 below provides an overview).

Table 21: Timeline: Key Meetings and Actions

Meetings or Actions	**Participants**	**Date**	**Purpose**	**Data Collected**
Workshop: Research Site 1	All healthcare professionals who worked at Site 1.	November 6, 2012 (pm)	Feedback and validate the fieldwork findings. Start planning for the modelling phase.	Participant feedback forms Fieldwork notes
Workshop: Research Site 2	All healthcare professionals who worked at Site 2.	November 15, 2012 (pm)	Feedback and validate the fieldwork findings. Start planning for the modelling phase.	Participant feedback forms Fieldwork notes
A key planning meeting	Key participants	November 30, 2012	The workshop findings were summarised and reflected upon. Key issues for action were identified.	Fieldwork notes Emails
Planning Phase: individual meetings with participants and key leads at sites and outside research site	Healthcare professionals from inside and outside the Trust and carer advisors	November 2012-April 2013	Plan actions in light of the fieldwork and workshop findings: e.g. develop tools. Applications submitted for funding to support development of one of the tools (DVD).	Fieldwork notes Emails
A key planning meeting	Key participants	February 26, 2013	Report planning progress.	Fieldwork notes
CDU Participants **1st Cycle of Action:** Research Site 1 & 2	Predominately CDU staff	April 2013-July 2013	Participants assess feasibility and acceptability of the new ways of engaging and working with carers and using the developed tools.	Fieldwork notes

Meetings or Actions	Participants	Date	Purpose	Data Collected
1st Evaluation Meeting Site 2 **Observing and Reflecting**	Predominately CDU staff	June 13, 2013 (pm)	Participants to share and reflect upon their findings.	Fieldwork notes
1st Evaluation Meeting Site 1 **Observing and Reflecting**	Predominately CDU staff	July 11, 2013 (am)	Participants to share and reflect upon their findings.	Tape recorded (Audio) Fieldwork notes
CDU Participants Action **2nd Cycle of Action:** Site 1 & 2	Predominately CDU staff	July 2013-September 2013	Another cycle of participants assessing feasibility and acceptability of the new ways of working with carers and using the developed tools.	Fieldwork notes
Participatory meeting Site 1	Key participant: Site 1	September 16, 2013	Key Participant reported progress.	Fieldwork notes
2nd Evaluation Meeting Site 2 **Observing and Reflecting**	Predominately CDU staff	September 19, 2013 (am)	Participants share and reflect upon their findings.	Fieldwork notes

7.2 The Purpose of the Workshops

An important pre-clinical phase task was the need to understand the problems from the perspectives of all involved, that is, the potential end-users of the intervention. An understanding of whose and what behaviours the intervention should target was also required. At the end of the pre-clinical phase, the fieldwork findings suggested that what prevented carers being prepared and receiving support in the chemotherapy treatment setting was predominately caused by practitioner and organisational behaviours. The intervention, therefore, needed to address these behaviours.

However, the fieldwork findings also revealed that what helped carers the most in this setting was an aware, skilled, empathetic, capable and confident health professional intervening in a timely manner, rather than for example, a support group or an information tool aimed at carers. The complex intervention, which should be developed for carers, was the health professional.

However, this was a participatory research study, which had an explicit intention to involve others to enable change. Although many of the participants had helped me identify the problems, they may not have had the same view or understood the problems in the same way. Therefore, a key objective of the workshops was to present a balanced overview of the fieldwork findings, using a facilitative approach. This was because practitioners needed to come to their own conclusions about what the problems were and how they would like to proceed with the modelling phase (if indeed they still did).

However, the main research question at the beginning of the modelling phase was as follows:

- How can healthcare professionals be enabled to prepare and support carers?

Further questions included:

- What would help healthcare professionals to have the courage to address carers’ needs?
- What would enable practitioners to manage the complexities of the interactions between patients, carers and themselves?

7.3 Workshop Conduct

At the end of the fieldwork, healthcare professionals working within the research sites were invited to attend a workshop (invitations and information sheets were distributed before the meetings). Although healthcare professionals from all disciplines were invited, only nurses and some allied healthcare professionals (AHPs) attended these meetings. Informed signed consent was obtained before the workshops started.

A workshop was held at each site. Each chemotherapy day unit (CDU) was closed for the afternoon. Both meetings continued for approximately three hours and included a comfort break with cakes and chocolates provided. A5 notebooks and pens were also distributed amongst the participants.

A power-point presentation was used, the aim of which was to retell the fieldwork participants' stories by covering a number of key issues and findings. The same format was followed at each workshop. 'Story-boards', were displayed around the rooms. These A2 posters presented key findings, participant quotes from interviews and questions used to prompt reflective discussion. The workshop content is presented in Table 22 below.

Table 22: Content of Workshops

Aims and Questions	
1. A brief overview and reminder of why this topic had been deemed important to research.	
2. A power-point presentation of the key fieldwork findings including:	
	a. What was currently going on in practice (e.g. it is relentless, a factory line, staff spinning plates, yet few complaints about patient care). b. The needs of carers during chemotherapy treatments: i. Carers need to be recognised and involved in the patients care. ii. Carers feel uncertain and frightened and need to know what to do and how to help the patient. iii. Carers require timely, manageable and relevant information from healthcare professionals. iv. Carers need permission from the service to enable them to seek support and advice from knowledgeable staff when required. v. Carers sometimes wanted an opportunity to talk on their own to a professional. c. Healthcare professionals appeared to be aware that carers had important roles and were vital to the safe delivery of treatment. However, these roles are often unacknowledged. Carers' needs were frequently ignored, unless there was a crisis. d. Barriers preventing healthcare professionals from engaging with, preparing and supporting carers were numerous and arose from the behaviours of the organisation, healthcare professionals, patients and carers.

Aims and Questions	
3. An exploration of why carers needs may be ignored:	
	Was it? a. Being unaware of carers' needs? b. A lack of professional understanding? c. A belief that supporting carers is not patient-centred care? d. Unmet training needs? e. Lack of leadership? f. Confusion about who was responsible for meeting carers needs? g. Having to manage difficult emotions? h. The patient can prevent involvement? i. "Opening the can of worms", it requires brave conversations? j. Staff lacking the confidence? k. Complex and advanced communication skills were needed? l. Professional codes of practice and guidelines were lacking? m. No time for staff to think ……..
4. An exploration with participants of what would help practitioners to enhance the preparation and support provided to carers:	
	Was it? a) Specific consultation and communication skills for working with carers? b) Are tools required? c) Using what we have more effectively, e.g. other colleagues, available resources and the pre-chemotherapy consultations? d) 'Time to think about carers' – educational interventions? e) Clarification of everyone's responsibilities towards carers? f) To determine an overall lead who will champion carers in the unit? g) Clearer professional codes of practice and guidelines? h) Being brave? i) About creating 'safe places' for staff to be able to think?'
5. What next? An exploration with participants on how to proceed:	
	i. We are innovators and can try things out?' ii. This is our work, how should that be recognised?
6. To thank everyone for their involvement so far.	

While presenting the findings, numerous questions were posed (as above). This aimed to prompt participants to discuss the findings, ensuring the main problems had been captured. A colleague with facilitation expertise helped conduct these workshops. She was not known to the participants. Her role was to ensure participants had 'a voice'. During the presentation she also encouraged the participants to challenge and question. She took notes throughout the meeting. Subsequently, these notes were written up in full.

At the end of each workshop participants were asked to consider, having heard the fieldwork findings, what they viewed the main issues to be. They were also asked whether they would like to proceed with the modelling phase of the study and, if so, how this should be accomplished. Both verbal and anonymised written feedback was sought. The feedback forms were to be returned in a sealed envelope to be left at the CDU reception desk.

7.4 The Workshop Findings

7.4.1 Site 1

The first workshop was held at Site 1 on November 6, 2012, at 2.30pm. Twelve participants attended, including: four clinical nurse specialists (CNSs), six CDU qualified nurses (including the unit manager), the unit's dietician and the CDU support worker (all these participants had been involved either intermittently or throughout the fieldwork). Apologies were received from a number of staff, citing work pressures. These staff included: a senior nurse and two oncology doctors.

The group who attended were extremely engaged and attentive. All participants contributed to the discussions. They provided further clarification on a number of key issues but concurred with most of the findings. Three slides in particular prompted a lot of discussion. The first contained a picture of a nurse spinning plates (Figure 9). A number of participants remarked both verbally and in writing that this was exactly how they felt most of the time when working in the acute cancer healthcare setting.

Figure 9: Spinning Plates (Bennett, 2012)

The second slide to induce initially nervous amusement, which then led to an in-depth discussion, was one entitled ‘the tale of two chairs’ (see Figure 10 below). As presented previously in chapter 5, the red chair was for staff when administering treatment and the hard uncomfortable chair was for patients’ visitors. The workshop participants remarked on how obvious something could be, but how easily it could be overlooked. This point was made again after the workshops by one key participant in an email. Her response can be seen below,

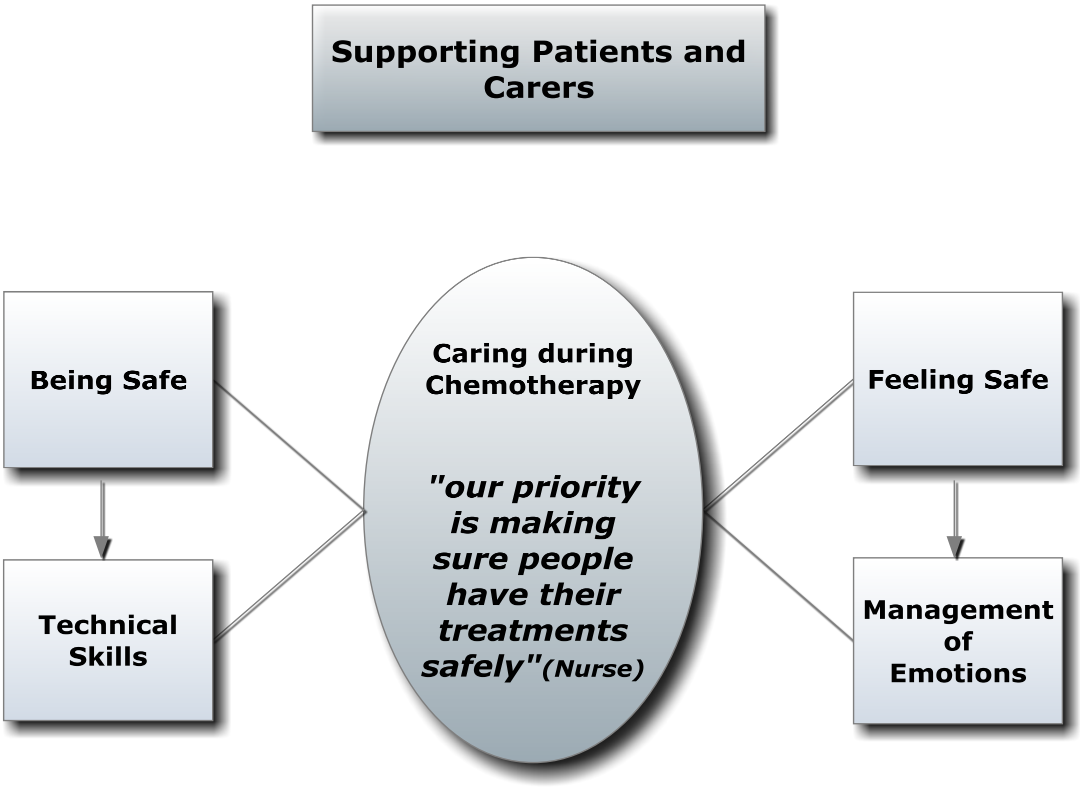
> *‘Please don’t remove the picture from your presentation I think it is a very pertinent point and actually we all feel that it demonstrates how you can become quite unaware of messages you may be sending. We did laugh but all feel it is a really simple and yet astute observation that provides a very relevant reflection point’. (Senior Nurse)*

Figure 10: 'The Tale of Two Chairs'

We often don’t see things in front of us: ‘the tale of two chairs’

The next slide, which triggered a very strong reaction from the participants, was one called, '*Being Safe – Feeling Safe'* (see Figure 11 below). Interviewed healthcare professionals had all stated that the role of the nurse in the CDU was to ensure that the patient received their chemotherapy safely. However, some interviewed practitioners firmly articulated that for '*patients to be safe'*, patients and their carers also needed *to 'feel safe'*. This requirement was especially vital when patients and carers were at home, feeling extremely uncertain, in-between treatments. Most interviewed carer participants had also expressed this view. However, meeting these needs required practitioners to not only be technically competent but also have a skill set, which was thematically described as '*managing the emotions in the room'*. This slide evoked an extremely impassioned response from one participant in particular, which was then endorsed by others in the group. While they all agreed this was an important need, they as healthcare professionals, also needed to 'feel safe' in order to do this type of work. They currently felt vulnerable, mainly due to recent challenging and uncertain conditions created through restructuring the organisation. They maintained that strong senior leadership was lacking within the Trust. Furthermore, this type of work required skilled input to manage emotions and develop relationships, for which they had little time and were ill-prepared to do.

Figure 11: 'Being Safe - Feeling Safe'



Supporting Patients and Carers

Being Safe

Technical Skills

Caring during Chemotherapy

"our priority is making sure people have their treatments safely"(Nurse)

Feeling Safe

Management of Emotions

The participants at the workshop expressed how they felt undervalued and frustrated (these feelings had also been conveyed in most of the interviews). They were working extremely long hours, in order to give care and support to patients; this had not been recognised or acknowledged by the organisation. One participant suggested she was '*never listened to by senior management'* and that '*we can't offer support if we are worn out'.* While another participant identified the constant need to *'put on such a professional front but it has been at a significant cost to us'.*

The pre-chemotherapy consultation was found to be an extremely important meeting but challenging to do. It is here when patients and those who support them are first introduced to the service and receive a lot of vital information. Patients and carers reported feeling overwhelmed in these meetings or alternatively they could not remember having had one. Carers were often ignored, although the patients had been asked beforehand by staff to bring someone with them. Patients had revealed they were rarely asked about their carers or the support they received at home. The workshop participants recognised that this session needed reviewing. One participant suggested that '*45 minutes per patient is a huge amount of wasted nursing time if it is not effective'*. They acknowledged, again verifying this fieldwork finding, that they had not received any guidance or training on how to conduct these complex meetings.

The participants agreed with the findings that there were gaps within the system, which created problems with continuity of care. The interface between the roles of the CNS and the nurses in the CDU was at times blurred. This led to some patients and their families being abandoned, without support from anyone within the service. Participants acknowledged that this problem was medically driven and historic (most CNSs came from a surgical background and had little chemotherapy experience and knowledge, so therefore left the patient and carer support needs to be addressed by the staff in the CDU).

A theme, which gained more prominence in the workshops, was the notion of '*where do we draw the line?'* Participants felt achieving patient-centred care and meeting all the patients' needs was difficult enough to accomplish in the current climate without also having to respond to carers' needs. However, participants recognised carers should be acknowledged and included within the patients' treatment pathway. This led to the presentation of the findings which addressed what would enable healthcare professionals to engage with, prepare and support carers more effectively in this setting. In this workshop a number of strategies were discussed and more were identified. Further training and support for the communication difficulties, which resulted from engaging with carers and especially when conducting pre-chemotherapy consultations, were ideas that particularly appealed. Participants also agreed with the finding that more professional guidance and clarity around carer issues, such as sharing information while maintaining patient confidentiality was required.

At the beginning of the workshop participants had been provided with A5 notebooks and pens. This was because the fieldwork findings had demonstrated that many carers write things down when in consultations. Reflecting on this finding with participants during fieldwork, had led to the idea of a '*support notebook'*. This notebook aimed at carers could contain some key advice and telephone numbers for contacting the unit, but would mostly have blank pages for carers to write whatever they wished. Many of the workshop participants had written in the provided notebooks. They agreed there could be a role for this type of tool.

Other ideas evolved in this workshop, including introducing an 'education clinic' and/or a DVD for carers. One participant suggested an idea for a '*fridge magnet'*. She had received one when her son had gone to university. On it were contact telephone numbers, identifying who she should call if she was worried about her son while he was away from home. She had found this fridge magnet extremely reassuring and comforting. She thought if a similar fridge magnet was given to carers, this may have the same effect; it would provide '*permission*' to call while also acknowledging the carer's essential role.

At the end of the meeting participants were thanked, they also thanked us. They said that for them, it had been an enlightening experience. On the returned feedback forms (N = 6), most acknowledged that being involved in this study had made them more aware of the needs of carers. They were more likely to actively engage with them in the future. They were also enthusiastic about continuing with the project.

7.4.2 Site 2

The second workshop was held at Site 2 on November 15, 2012. This workshop had originally been scheduled for October 26, 2012 but had been cancelled by the CDU Sister because she was ill. On arriving to the unit it was found that the room booked for the meeting was being used for another meeting and most of the permanent CDU nurses were off work, on sick leave, including the Sister. The overall lead for the cancer department could not attend, as she had been called to an emergency Trust meeting. I queried whether the workshop should go ahead. However, with the help of another senior nurse, an alternative venue was found, the patients' lounge on the ward. Although not ideal, it was spacious enough to accommodate the meeting.

After a delayed start, ten participants attended, including: six CNSs, two CDU nurses, one research nurse and a CDU support worker. The CDU nurses and research nurse had not been involved in the previous phases of the study. However, all confirmed they had received the workshop invitation and information sheets by email.

The same format previously used at Site 1 was followed and the ensuing discussions were similar. However, there were slight variations in the themes. This was likely due to the larger proportion of CNSs who attended this meeting with less CDU nurses, compared with the group who had participated at Site 1.

All the CNS who attended this meeting had worked at the Trust for ten or more years, and most in their current CNS role for over five years. Many remembered how it used to be, when they had smaller caseloads, the service was less busy and they had more resources, for example, an onsite counsellor. They agreed the work was relentless. They described how patient care had suffered as a result. They had little time to think about what they were doing or support other nurses in their work. They concurred with the finding that most patients and carers struggled to understand and retain much of the information they received in the initial consultations. One participant also reiterated that '*everything happens so quickly in this stage of the patient pathway, it is difficult to know how best to provide information'.* They agreed this was an area which definitely required more development. They reiterated the finding that other healthcare professionals, for example, surgeons, did not perceive supporting carers was part of their role. As a consequence they (nurses) received very little support from other members of the multi-disciplinary team for this type of work. Yet they all agreed, when one participant stated *'carers are the unsung heroes of the treatment pathway'.*

Most of the participants said they were '*increasingly letting patients down'*. Similar to participants at Site 1, participants discussed in-depth the notion of '*when do you draw the line in the sand'* and '*when is good, good enough?*' The participants felt strongly that they were unable to do '*everything*' for patients and carers. More resources were needed. However, most acknowledged that some resources were underutilised by staff, for example, the information support centre at Site 3.

All the CNS participants described how they had mostly learnt their consultation and communication skills '*on the job'* and *'from each other'*. They would have valued more training for this aspect of their work. They acknowledged that most of these meetings were now conducted behind closed doors, offering limited opportunity for nurses to learn from role models. They seemed to particularly like the idea, offered by one practitioner, of CNSs and CDU nurses, '*buddying up'* to conduct pre-chemotherapy consultations together. Jointly conducting these, if only for a few, would enable the CNS and CDU nurse to learn from and support each other.

The workshop participants agreed the '*carer support notebook'* was a good idea. One participant, a CNS, particularly wanted to take this idea forward and offered to work with others in the unit to identify what the notebook should look like and contain.

Verbal feedback suggested they had found the presentation interesting. A lot of the findings however, had not surprised them. Although one, a support worker, remarked that it was '*amazing*' just how much had been uncovered. Written feedback, (n=4), suggested that being involved with the study had increased their awareness of carers' needs and they were more likely to include them in discussions with patients.

7.5 Planning

After the workshops, a meeting was held on the November 30, 2012 with three key participants (these were senior nurses within the units, who had stepped up to lead and move the actions forward within the sites). Two of these participants had attended the workshops (one on either site). The Sister from Site 2 CDU had been invited but was unable to attend due to illness. The purpose of this meeting was to discuss the main findings from both workshops and agree on how the work should proceed. The key lead participant from Site 1, also shared an action which had been already been instigated. New chairs for visitors to the CDU had been ordered (Figure 12). These arrived in February 2013.

Figure 12: New Chairs for Visitors: Site 1

At this meeting it was agreed that an '*away day'* for as many of the CNSs and CDU staff as possible would be organised. The purpose of this all day event would be to try out different strategies for engaging, preparing and involving carers. Carers, from the carer advisory group, could contribute to this away day. One suggestion was to include role play sessions. The nurses could 'act out' interactions with carers and receive support from each other on how best they could manage these. It was envisaged that bringing the two groups together, for example, CNSs and CDU staff, with the carers, would provide learning for all. It would also be an opportunity to thank everyone for their commitment to this work, by providing a nice venue away from the hospital, with perhaps some sort of fun activity added on to the day. All three participants, wanted to take forward the idea of the fridge magnet and support notebook. One participant in particular, who had attended the workshop at Site 2, had already started designing the notebook.

By the beginning of February 2013 very little progress had been made with organising the *'away day'* and development of the tools had slackened. It was difficult to engage with the key participants. They were slow to respond to emails and were rarely available on visits to the research sites. However, during this period I was also deeply immersed in data analysis, so visits were sporadic. Eventually, a second 'planning' meeting was held on February 26, 2013. The Sister from Site 2 was again unable to attend due to illness. At this meeting the findings were briefly reiterated, progress with the tools discussed and strategies for evaluating these identified. The feasibility of convening a staff '*away day'* was also reconsidered. The key participants acknowledged that things had been '*pretty tough'* at the Trust. Since the last meeting in November, their priorities had been to manage the numerous re-organisational changes and the '*winter pressures'*, created by staff illness, increased patient admissions and the Christmas holiday season. They were very apologetic but they had struggled to find time to engage with this work.

All three key participants thought an '*away day'*, although still a great idea was no longer possible. They could not justify closing the units for a whole day nor could they envisage staff, in the current climate of the Trust, wanting to attend this event on a Saturday, their day off. However, these three participants really wanted to continue with developing the tools. How the developed tool could be evaluated, in light of the current pressures in the units, was also discussed. They suggested various strategies. These included undertaking a pre-test, post-test evaluation of the notebooks, for example, questionnaires to be given out by staff to carers before and after the carers received these tools and focus groups with staff. The outcome of this meeting was reported to the project advisors and supervisors. On reflection it was decided that no formal evaluation would be undertaken with carers and patients at this time. Rather the feasibility and acceptability of the tools would be evaluated through focus groups with staff after they had tested the new tools over a period of eight weeks. It was thought that this would create less pressure on the staff. There was also little time to submit a new application to IRAS seeking ethical approval for undertaking a carer and patient survey. The key participants subsequently supported this decision.

After this meeting a flurry of activity ensued, including a series of participatory meetings, with individuals and groups of participants coming together from each site, email correspondence and telephone conversations. The purpose of these interactions was to design the fridge magnet and support notebook and other potential strategies identified by the workshop participants. Carers from the carer advisory group played a significant role in this phase, helping to design these tools. My role, as this phase progressed, was to assist participants to design the tools, have them manufactured and act as a conduit between the participants at the research site and members of the carer advisory group.

7.5.1 Designing the Tools

The support notebook was predominately designed and developed by the participants. As previously highlighted, one CNS in particular (a key participant) took the lead and wrote the first skeleton draft. This rough copy was then sent by email to other participants, for example, CDU staff and CNSs in the Trust for their input. With their approval I forwarded it to some members of the project advisory group and all members of the carer advisory group. I had the task of collating their feedback, (verbal and email correspondence) and sending it to the participants at the research site.

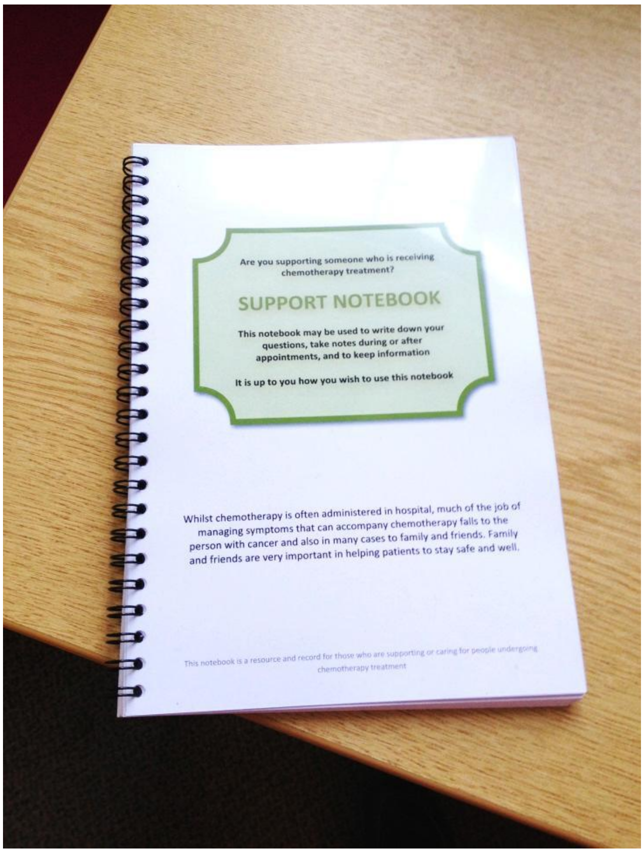
A lot of consideration was given to the content and presentation of the notebook. It was kept small, A5 size, so it could be easily carried. The participants decided not to use the term ‘carer’ on the notebook, preferring to use the term ‘family and friends’. Quite a few issues became controversial. One participant’s idea to have a picture of a flower on the front of the notebook (Figure 13) was rejected by most. The notebook went through at least nine iterations until all were satisfied. The final draft contained key advice on what side-effects to look for and what to do if problems arose, important contact telephone numbers and a series of questions to help guide the support person (Appendix 19). These tools were reasonably inexpensive to produce, 750 fridge magnets (375 for each site) cost £641.26. The cost of 370 support notebooks (185 for each site) was £765.00 excluding VAT. These costs were met through my research budget.

Figure 13: The Controversial Flower

'What flower is that? It looks like flowers you have at a funeral' (Email: Project Advisor)

'Please find my initial thoughts in relation to the booklet which is a fantastic idea and resource. Sorry to be a pain but they are my initial thoughts. Why do you need to show the flower? This can be off putting to some people who may associate flowers with being old.' (Email: Carer Advisor)

Figure 14: The Support Notebook



Are you supporting someone who is receiving chemotherapy treatment?

SUPPORT NOTEBOOK

This notebook may be used to write down your questions, take notes during or after appointments, and to keep information

It is up to you how you wish to use this notebook

Whilst chemotherapy is often administered in hospital, much of the job of managing symptoms that can accompany chemotherapy falls to the person with cancer and also in many cases to family and friends. Family and friends are very important in helping patients to stay safe and well.

This notebook is a resource and record for those who are supporting or caring for people undergoing chemotherapy treatment

The fridge magnet was easier to design (Figure 15, image is distorted to protect anonymity). The manufacturing company produced only a number of formats, which could be used. However, once again there was much debate concerning what terms to use (see email excerpts below). Some participants did not want to use the word '*worry'*, favouring the term '*concerned*'. Another example was rather than use the term '*help you'*, some preferred to use '*advise*'. Participants finally agreed to use the phrase '*a professional will always be there to advise you'*.

> *I wonder if 'help' is the right word if we are trying to empower people - I will have a look on the alert card - I think it might be good to tie in together. (CDU Nurse)*
>
> *'In relation to the phone does anyone still use these types of phone could the message not be placed on a mobile type of phone or screen. Also the phrase 'help' conjures up thoughts of calling as a last resort when I would hope that people would feel comfortable with sharing any concern at any time before it reaches the stage that they feel that they need to shout help' (Carer Advisor)*
>
> *Yes I like the old phones too! It's still the icon you think of as a telephone I think - or is that because I am ancient and actually it's an IPhone these days. I think 'concerned' almost plays it down a bit - but we are backing this up with pre-treat consultation and ALERT card so I think we should try it and see. (CNS)*

Figure 15: The Fridge Magnet

7.6 Acting

When the fridge magnets and support notebooks were manufactured and delivered to the sites, CDU nurse participants began using them, as agreed with the key participants. This first cycle of acting started in April 2013. How, when and why they used these tools was up to the participants within the units. I gave no guidance or instructions, nor any formal measurements to evaluate the use of the tools at this stage. The aim was for participants to explore the usability and feasibility of the tools for themselves. My role, therefore, was to support the key participants who had taken on the roles and responsibilities of managing these changes within the units. Informal meetings were held with the key participants and the Site 2 CDU Sister who been unable to attend the previous meetings, during the eight week period. One of these key participants also managed the process of informing others, including doctors and CNSs within the Trust, of the changes being initiated in the CDUs.

7.7 Observing and Reflecting

7.7.1 Evaluation Meeting Conduct

After approximately eight weeks of the CDU staff trying out the new tools, meetings were held with participants (one at each site) to explore their experiences of working differently with carers and patients. The nurses called these meetings, '*evaluation meetings*'. The key participants agreed to distribute the invitations, information sheets and consent forms. Once again, the CDUs were closed allowing the meetings to be conducted with as many staff as possible. The meetings lasted approximately two hours. Drinks and cakes were provided. The meeting at Site 1 was audio tape recorded, but not at Site 2.

My role in these meetings was to facilitate the group discussions. A colleague, who had experience in conducting this type of research meeting, helped to facilitate by encouraging the participants to contribute. She also recorded notes and helped me to reflect upon the experience after the meetings.

7.7.2 Evaluation Meeting Findings: Site 2

The first evaluation meeting was held at Site 2, on June 13, 2013 at 2pm. Nine participants attended including five CDU nurses, one support worker, two senior nurses and one CNS. Four of the CDU nurses were relatively new members of staff and had not been involved in the previous phases of the study.

On arrival to the unit some of the CDU nurses were still working, administering treatments. It was also evident they were annoyed. A CDU nurse, who had participated in the fieldwork but not the workshop, informed us that the CDU Sister was off sick (the Sister had previously agreed to organise this meeting). The CDU nurse disclosed they had not been told why this meeting had been scheduled. It transpired they had not received the study information packs. I also realised that there was a box full of support notebooks under the treatment room desk. It was clear that something was amiss. I sought out a senior nurse (key participant) who had participated in the planning meetings and explained that there appeared to be some problems. After a short discussion we realised the study information packs had not been distributed as previously agreed. The senior nurse recommended that the meeting should go ahead, as patients were not scheduled for the rest of the afternoon. The time could be used to explore what had happened.

On returning to the treatment room, it was found that most of the patients had now left and those still there were in a side-room. The CDU nurses told us the meeting could start. The chairs were set up in a circle and everyone had a drink and cake. At the onset most of the CDU nurses were defensive and annoyed. They said they had not been made aware of what was going on and had felt excluded from the process. I responded by apologising as it seemed we had '*clearly missed a step*'. The purpose of the meeting was then explained. The CDU nurses became apologetic and admitted that they had not distributed the notebooks to carers. Although they were aware that two members of staff had. The fridge magnets had been distributed to patients but not to carers. They thought these were really useful, as one participant explained the *'patients had the number easily to hand'.*

The CDU nurses wanted to hear more about the fieldwork findings as most had not participated in the workshops. The slide entitled the ‘tale of two chairs’ was shown (Figure 10), this made most giggle. However, they grasped the significant message behind the picture, ‘*even the most caring nurse misses the obvious*’. This provoked a discussion among the group about the inadequate facilities and lack of space in the unit. The CNS participant talked about the notebooks and how the idea had come about. One of the CDU nurse participants thought it was like a ‘*contact book, children bring home from school*’. The CNS shared with the group that she had wanted to use a picture of an amaryllis on the front page, but joked that some of the project and carer advisors had called it a ‘*death flower*’. This made everyone laugh. People began to become really engaged. On reflection this was because we, the facilitators and senior nurses, had provided space and time, enabling the CDU nurses to share their frustrations. We had also apologised.

The CDU nurses raised many of the previously identified barriers to engaging with and supporting carers. However, one of the CDU nurses admitted she had personal experience of being a carer. She talked, at times emotionally, about how difficult it was to support someone through chemotherapy. Although the CDU nurses liked the idea of the notebooks, they acknowledged they were apprehensive about using them. The CNS who had already given the books to carers in consultations shared with them her finding that at times it ‘*felt tricky*’. This prompted in an in-depth discussion of how hard it was to introduce the notebook to carers and conduct the pre-chemotherapy consultation with patients (which the CDU nurses kept calling a ‘*chat*’). The CDU nurses thought that perhaps the pre-consultation might not be the right venue for introducing the carer support notebook; they questioned whether another member of the team, for example, the CNS could do this work. One participant also suggested that most CDU nurses had not ‘*had mental health nurse training*’. Initiating a discussion about whether CDU nurses truly needed to have this.

However, the CDU nurses did not appear to agree with the fieldwork finding that pre-chemotherapy consultations were challenging to conduct, (yet many interviewed nurses had raised this issue). Although they could see how some nurses might find balancing the amount of information problematic and yes it sometimes did feel to them like a ‘*tick-box exercise*’. One of the CDU nurses remarked that she did find it difficult when patients started crying after being told about side-effects. The senior nurses in the group, however, acknowledged and reiterated how difficult they found this aspect of their work. They thought even though they were experienced nurses they could do with more training in this area. The CNS shared with them the idea for a training DVD (to be discussed later).

At the end of the meeting the group was asked how they would like to proceed. It was made clear they did not have to continue with the project. However, all the CDU nurses wanted to have '*another go at giving out the notebooks to carers'*. They wanted to think about everything that had been discussed and have another opportunity to have an evaluation meeting. They were surprisingly upbeat, without prompting all the CDU nurses thanked us. They said it was '*really good to talk and be heard.'* After the meeting a letter was sent to all the participants. This summarised the meeting and agreed actions. Subsequently, one of the senior nurses emailed me that all the CDU nurses had shared with her that '*they had felt really listened to and valued'* in this meeting.

7.7.3 Evaluation Meeting Findings: Site 1

The next evaluation meeting was held at Site 1, on July 11, 2013, at 9am. The unit was closed for two hours. The staff warmly welcomed us when we arrived at the unit. The meeting was held in a small, training room away from the main treatment area. Four CDU nurses attended, one of whom was a key participant. All had been involved in the previous phases of the study and conducted pre-chemotherapy consultations. One member of staff could not attend because of illness. The unit support worker opted not to attend the meeting, as someone was required to monitor the phones. All had received the study packs and signed the consent forms. This meeting was audio tape recorded.

The participants were eager to share their experiences and started talking before the tape-recorder was switched on. All had offered notebooks and fridge magnets to carers. The nurses liked the designs and thought nothing needed adding to the content. One participant described how it was now '*really good to have something to give to the carers'*. Although another added that it was difficult to know sometimes who the best person, for example, which carer, should be offered the notebook. Sometimes they found the first person who came with the patient was not necessarily the main support person. Alternatively, when a patient came with two support people, for example, both daughters, they struggled to know who to give the book to. Different strategies had been used, one participant highlighted that *'ultimately it is the patient's decision'*.

All had observed carers returning to the unit with the notebooks, they had clearly been using them. One participant stated that *'it seemed to make people feel valued, we are doing something for them, we are giving them permission to be involved, and it was inclusive'*. The other participants concurred and one added that '*it felt important to have something physical to give carers, it prompted me'*. To clarify, I asked '*was it the notebooks that enabled you, or could you have done it without*? All the participants agreed that the notebook gave them a way in, something to approach the carer with, which was acceptable to the patient. While another participant suggested that it '*helped everyone in the room to feel involved, not just the patient*'.

One participant acknowledged that she found trying to approach the carer very difficult when the patient was in the room, '*it is a difficult conversation'.* She felt they could undermine or upset the patient if they handled the inclusion of the carer badly. They shared different techniques for introducing the notebook. One participant was 'up-front' and told them exactly what the notebook aimed to do, while another introduced '*it as something you might find useful'.* They thought using the notebook had not particularly increased their workload. Nor did they think the tools had necessarily increased the telephone calls to the unit, if anything the telephone conversations were now more appropriate and direct.

All the participants agreed they really liked the fridge magnets. They found that most of the patients and carers had appreciated them. One participant said the '*magnet was simple, the message is JUST RING*!' While another suggested that both tools had '*provided people with a peace of mind, as patients know they are being treated with something that could cause life threatening side-effects'*. One participant raised a problem. '*What happens if the fridge door is made of wood*?' This made all of us laugh. Another suggested that '*they could put it on something else near the phone'.*

However, one participant suspected that a particular patient group did not like the magnets. These were the Black African breast cancer patients. Indeed these patients seemed very pensive about both the tools. The nurses felt this was because they did not want their families to know they were having treatment. It had also raised the nurses' awareness that many of these patients did not bring someone with them to the consultation meetings. A problem they felt needed looking into, perhaps an area for future research.

The discussion turned to the pre-chemotherapy consultation. They all stated how difficult it was to get the information-giving process right. One participant felt there was a *'fine line between respecting the patient's wishes* [if they did not want information] *and actually being safe in terms of the amount of information given in this session'*. The all felt strongly that the patient and carer needed to know the essentials to be safe, for example, monitoring for sepsis and knowing who to call when there was a problem.

One of the participants raised the lack of continuity between different members of the team as an on-going problem. She felt that the CNS involvement was sometimes fragmented and their assessments should be more '*holistic*' and include carers. Discussion around the role of the CNS and their interface with the CDU ensued. The participants felt the links could be stronger between the two. They thought CNSs should formally hand-over patients, although they acknowledged that CNSs had large case-loads and finding time to do this could be an issue. They felt the CNS, however, should be involved in the whole patient pathway. Different strategies to address these issues were discussed. They felt this was something they needed to tackle fairly soon.

They raised other problems, which made their work extremely difficult and frustrating at times, increasing numbers of patients, lack of space and not enough staff. Yet they felt that they did, as one participant put it, '*a good job in the circumstances'.* They were asked what they wanted to do now. Eager to continue the work, they said *'bring down more notebooks and magnets, we need more*!' However, they did not think it essential to have another formal evaluation meeting; choosing instead to work with each other on any problems as they arose. However, it was agreed that I would continue providing support and the key participant (the lead change agent) would feedback progress. Subsequently, more fridge magnets and 'support notebooks' were ordered and delivered to both sites.

The key participant at site 1 and I met on September 16, 2013. The notebooks and magnets were still being handed out by the CDU nurses. Responses from patients and carers continued to be positive, although the nurses preferred the fridge magnets.

7.7.4 2nd Evaluation Meeting Findings: Site 2.

The final evaluation meeting for this phase of the study was held at Site 2 on September 19, 2013 at 9.30am. Again the units were closed. The meeting was held in the main treatment room. Three CDU nurses and a CNS participated. Apologies were received from two people. One of the CDU nurses had a doctor's appointment and the service's lead cancer nurse had been summoned to a Trust meeting.

One of the senior nurses asked to speak to me before the meeting started. She admitted there were currently a lot of problems on the CDU. People within the unit had not been working well together. The Sister was off sick again and things were difficult for the staff. The senior nurse thought that the meeting should still go ahead, even with small numbers, as the nurses who could attend had been using the notebooks and they wanted to have this meeting.

The meeting started with checking consent, ensuring everyone was happy to be there. I told them we just wanted to hear how things had been for them since the last meeting. One of the CDU nurses described how she had given the support notebooks to a 12 year old girl who was attending consultations and treatment sessions with her mother. This young girl acted as a translator for her mother as she could not speak English. The CDU nurse thought the notebook had been a really powerful way of helping this girl and her mother. She stated that the doctors had found it useful too; as it helped them to assess how the mother had been coping with treatment (the daughter had used the notebook like a diary). This CDU nurse said '*we are all giving these notebooks out now'.* They all acknowledged the notebooks were *'much better than scraps of paper'.* They had seen carers using the books and this had been encouraging.

The CNS shared with the group how one carer had transferred the support notebook idea on to his mobile phone. She said other carers had also suggested it could be adapted into a piece of software (an app) for downloading onto mobile phones and other personal devices. Patients were also using the notebooks. The participants had found that the carers really liked the tools, *'it gave them peace of mind and numbers they could call'*. The notebook gave the carer '*permission to be involved and that they were acknowledged as part of the team'*. They had found '*no downsides to these tools'.*

Since our last meeting all four participants told us that they had reflected a great deal, especially on how they conducted the pre-chemotherapy consultation. One participant acknowledged that they all had discussed what questions they should ask patients and their carers before they *'launched in to give information'*. Another described that she now felt it was more important not to tell them everything that could possibly happen; rather they should ask patients what they needed to know. As a consequence, this nurse found that patients had all wanted different information and support. Yet, the process had felt less overwhelming. Furthermore, they realised that they did not have to provide all the information at the first meeting. These participants recognised that patients and their carers could take the information sheets away with them so they could read it at a later date. The information process should continue throughout the treatment rather than be a '*one-off'* occurrence. One of the CDU nurses also revealed that she now sat in a comfortable chair with the patients and carers, rather than at a desk. She felt this made her '*look more human and less formal'*.

The participants were asked what it had felt like, to implement change when there was so much uncertainty and flux in the Trust. They all agreed that being involved with this work had been positive. One of the CDU nurses commented '*it was good to be reminded that they needed to keep the foundations of good patient care'*. She said it was about '*being responsive and safe'*.

The participants were asked what else would help them to enhance the support for carers. One idea was for an assessment tool, '*we could draw a family tree like they do in palliative care'*. Another reiterated idea was for a support/education group aimed at carers. The CNS also told us they had submitted a very recent application to a local charity for funding. If successful the money would provide Citizen Advice Bureau (CAB) support for patients and carers at the unit.

They also disclosed that now the unit had merged with another site, work was due to commence on developing a new shared unit philosophy, which would incorporate carers' needs.

The participants were asked what they thought people and in particular other nurses should be told about this study. One responded with '*don't be afraid to involve family members and carers. It is not just about the patient, they are part of a network, and it is a family journey which will impact on all and not just the patient'*. They were also asked what training healthcare professionals should have, to enable them to do this work. They thought there should be mandatory training within the Trust, everyone should attend. They also believed that professional guidelines would help staff feel more confident when engaging with carers. One participant suggested that carers' needs and how to support and communicate with carers should be a component of all national chemotherapy training courses. They thought the idea for a DVD presenting the process and communication skills used in pre-chemotherapy consultations would be good for new staff. Finally, they all acknowledged that what had been really useful was having *'time out'*, to listen and reflect with colleagues about their experiences.

7.8 More Planning, Acting, Observing and Reflecting.

Reporting all the communication and collaborative work that transpired during this project is challenging. As is common with most action research projects there were numerous 'spin off actions', which resulted from the participatory nature of this work. Many of these are outlined below in Table 23. The participatory meeting, referred to as an expert consensus meeting, will be discussed in more detail.

Table 23: Other Participatory Meetings and Actions

Meetings or Actions	**Participants**	**Date**	**Purpose**	**Data Collected**
Attended SAGE & THYME Training	Project advisor	Dec 13, 2011	A 3 hour communication skills course, aimed to equip healthcare staff with skills to manage patient' and carer' distress. It was initially thought that this might be a potentially useful training tool/intervention for staff.	Fieldwork notes
Participatory meetings	Healthcare professionals from across region and carer advisory group members	September 2012 – March 2013	Application to a regional charitable organisation for funding to support development of one of the tools (DVD)	Fieldwork notes Emails
Visit to regional Cancer Centre	Network Lead Chemotherapy Nurse and CDU	September 20, 2103	Observe other nurses conduct pre-chemotherapy consultations	Fieldwork notes

Meetings or Actions	Participants	Date	Purpose	Data Collected
	nurses			
Expert Consensus Meeting	Healthcare professionals from across the region	February 4, 2013	Meeting aimed to generate ideas and gain consensus re: the purpose and procedure of pre-chemotherapy consultations	Participant feedback forms Fieldwork Notes Emails
Visit to another Cancer Centre (outside of region)	Key participant at Site 1	April 12, 2013	To explore a different process for conducting pre-chemotherapy consultations e.g. in groups rather than one-on-one.	Fieldwork Notes Emails post meeting
Participatory Meetings	Healthcare professionals across region and carer advisory group members	May-June 2013	Application submitted to a national charity for funding to support development of one of the tools (DVD) June 10, 2013	Fieldwork Notes Emails
Leading Empowered Organisations (LEO) course	Two key participants from Site 1	June 1 and 2, 2013	Attendance at a two day event described as a 'transformational leadership course' which aimed to develop knowledge, skills and behaviours required for effectively leading and managing change in NHS organisations.	Notes from course
Family and Carers Listening Event (Mental Healthcare)	n/a	June 13, 2013 am	This event aimed to bring carers and mental healthcare workers together to raise awareness of carers' needs and to promote the updated Triangle of Care (2013) guidance.	Notes & Contacts
SAGE & THYME Meetings	Healthcare professionals from across region	May-Sept 2013	Meetings with CDU staff and other healthcare professionals to explore the potential of SAGE & THYME for helping enhance staff confidence for working with carers.	Notes
Clinical Nurse Specialist Meeting at Research Site	CNSs	June 17, 2013	Presented findings from the pre-clinical phase; explored how they as CNSs could work more effectively with carers and support other healthcare professionals to do so.	Fieldwork notes

7.8.1 Expert Consensus Meeting and Funding Applications

A major emergent theme was the difficulties nurses and other practitioners have in managing the pre-chemotherapy consultation and meeting the different needs/expectations of those present. The problems identified at the research site were also of interest and concern to healthcare professionals based at the local regional cancer centre, for example, the network consultant and lead cancer nurses (many of these staff worked across the research sites and other Trusts in the region). Some of these healthcare professionals had also been members of the project advisory group.

These regional lead nurses arranged for me to visit the CDU within the regional centre. The purpose of this visit was to observe how their staff conducted consultations. Three CDU nurses participated; they had previously been fully informed and were aware of the purpose of the observations. During the consultation sessions, in between patient appointments, all three nurses discussed the challenges they perceived they had when conducting these meetings. These included balancing their need to inform of adverse effects with the patients' wishes of not wanting to know too much, managing the 'expert' and very depressed patients. Another challenge was when palliative chemotherapy was administered to patients who seemed to have little understanding of what this meant. Interestingly, none of the nurses while observed acknowledged the person who accompanied the patient. Furthermore, none of the staff had received training for this aspect of their work. After the observations, the nurses and the lead chemotherapy nurse reflected upon the consultation process with me. All were in agreement with many of research site participants that there was an urgent need to develop this aspect of chemotherapy nursing care.

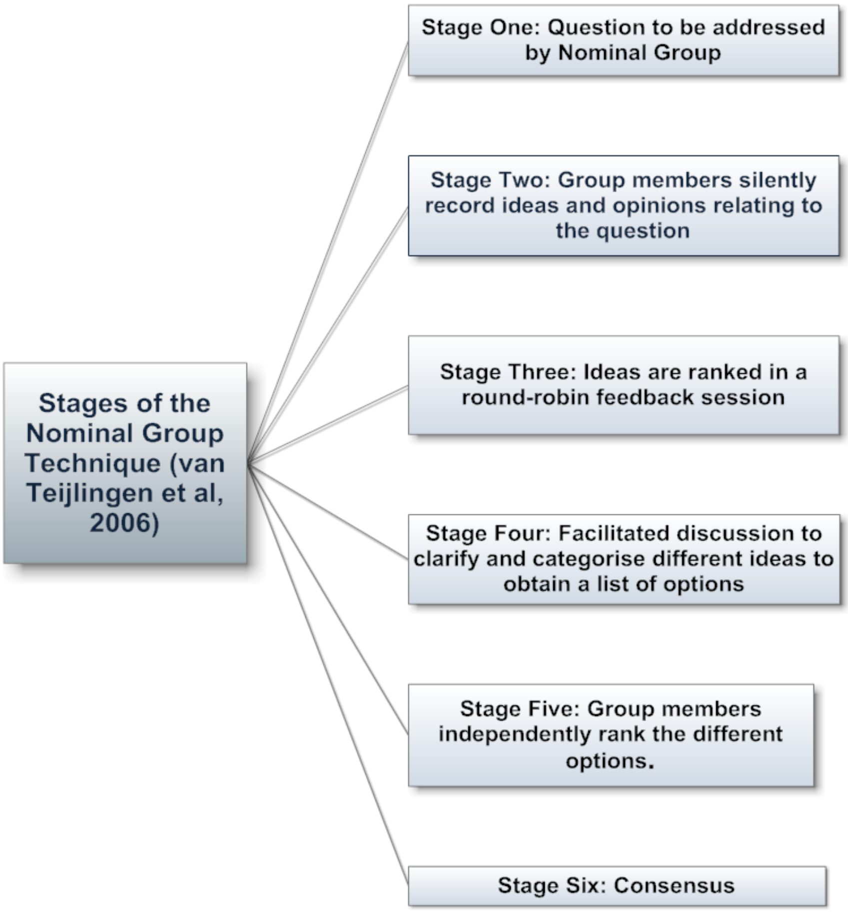
Meetings were held, between August 2012 and June 2013, with various members of the action research (site) team and staff members from the regional cancer centre. The purpose of these meetings was to explore the aim of the pre-chemotherapy consultation and to seek support for submitting an application for a service development grant. This funding would be used to develop guidelines and a training tool, for example, a DVD. To underpin this collaborative work we decided to convene an expert consensus meeting.

The consensus meeting's findings were to be used to inform a shared understanding of the pre-chemotherapy consultation. This understanding would then provide the basis for the development of a professionally produced educational film; presenting practitioners and actors demonstrating a person-centred approach (inclusion of patients and carers) in a consultation. This idea had been suggested by carer and project advisors. Demonstrations of how it should not be conducted, for example, scenarios revealing poor practice would also be demonstrated. It was envisaged that the film would be disseminated via DVD and as an e-learning based resource. It would be used as a component of on-going, facilitated, 'in-house' training and support for staff who work in the chemotherapy setting.

The two-hour meeting took place on February 4, 2013. Twenty-five invitations were sent to those considered experts working in the cancer regional network. These included representatives from all disciplines, for example, medical, nursing, psychological support, pharmacy and education. Fifteen people attended. Apologies were received from nine practitioners, however, most wished to remain involved. For this meeting a modified version of the nominal group technique was followed (see Figure 16 below).

This technique is extensively used in healthcare research for the development of guidelines and should offer a structured, transparent and replicable method of synthesising expert judgements (Raine et al, 2004; Gallagher et al, 1993). The process was conducted by an experienced service development facilitator. Although leading on this stream of work, my role in this meeting was as a participant. Notes were recorded and transcribed after the meeting.

Figure 16: Stages of the Nominal Group Technique



The meeting’s objective was to generate ideas and gain consensus for the following:

1. What is the purpose/goal of the pre-chemotherapy consultation?

2. What would demonstrate an effective pre-chemotherapy consultation?
3. What would you not want to see a practitioner do/say in a pre-chemotherapy consultation?
4. What would be acceptable as the minimum amount of information to be communicated in a pre-chemotherapy consultation?

To start the process the participants were asked to independently record their answers to the above questions. The participants were then split into groups of three. After discussing their answers, each group ranked in order of priority their ideas. These were reported back to the group, which prompted a facilitated discussion between everyone.

During the meeting there appeared to be a lot of confusion and debate, especially between doctors and nurses, about the objectives and content of the pre-chemotherapy consultation. However, the overall purpose of the pre-chemotherapy consultation did emerge from a post meeting analysis of all the findings, but especially the written anonymised responses, as follows:

> *'The pre-chemotherapy consultation provides an opportunity for the practitioner to elicit patient and carers' concerns, to orientate them to the service and treatment and exchange information which aims to enhance patient and carers ability to manage safely at home while inducing a sense that they have on-going support from the service.'*

While participants managed to provide answers for most of the questions, consensus was not achieved. Reaching only stage four of the modified nominal group technique, it was evident more time was needed to do this work.

Discussions with the lead nurses after this meeting led to an agreement that if the work was going to continue, money would be required to support the project. Consequently, applications were submitted, seeking funding, firstly to a local charitable organisation for £20,000 and then to a national voluntary organisation for £30,000. Unfortunately both applications were rejected. The feedback received suggested the funders had concerns about the sustainability of the film.

However, as can often happen with participatory research, the ideas from this work were taken forward and acted upon before a systematic and recorded follow-up to the meeting could take place. The initial findings were reported by some of the participants to the regional cancer network chemotherapy group. Nurses within this group then continued with various aspects of this work, including seeking an understanding of the purpose of a pre-chemotherapy consultation, via email survey to other chemotherapy lead nurses across a much wider region. Although the other members of the 'expert' group were informed, it was only after the lead nurses had discussed the problems at the regional meeting and actions had been initiated. This was frustrating and some difficult conversations ensued, especially concerning ownership of the work.

7.8.2 Other Visits, Meetings and Actions

As can be seen in Table 23 other meetings and actions took place during the modelling phase. This included networking with other healthcare professionals who worked in a regional mental health Trust. In collaboration with the Carers Trust and carers (service users) the Trust had been instigating strategies to raise awareness of carers' needs amongst frontline staff. It was clear they shared similar complex dilemmas as those found in this study. Engaging and communicating with carers was a particular challenge. This Trust had adopted a 'carer awareness' strategy as outlined in The Triangle of Care (Worthington et al, 2013). They were also incorporating a communication skills training model, SAGE & THYME (Connolly et al, 2009) within their 'carer awareness' trust-wide training approach.

Finally, a potentially useful intervention suggested by some of the participants was the idea for a pre-chemotherapy education clinic. A key participant from Site 1 and I visited a large cancer centre, in another region of the UK. The purpose was to observe a recently instigated group information/education intervention led by experienced chemotherapy nurses. It was an interesting visit, which provided some thought-provoking insights. In-depth detail has not been provided here of this visit, as informed consent was not obtained from those we observed. However, the findings were subsequently reported to the participants at the research sites and members of the advisory group. On reflection, it was decided that group educational sessions were not interventions that should be developed to meet the aims of this study. While there were benefits, it was a resource and staff intensive intervention. A cancer centre could perhaps handle the requirements for such an initiative but a smaller unit could not. It was not 'person-centred', nor inclusive of carers and information provided about chemotherapy was extremely general. Undertaking such an initiative would, therefore, still necessitate the need for a nursing one-on-one meeting with patients and their support person.

7.9 Chapter Summary

This chapter has provided an account of the participatory work and many subsequent actions, which occurred during the modelling phase of the project. The final evaluation meeting held at Site 2 on September 19, 2013, signalled the end of data collection for this doctorate study. This does not, however, suggest that the work has ceased. As outlined above, many actions, initiated as a consequence of this research, continue.

Chapter 8 Discussion

'A Professional Will Always Be There To Advise You'

8.1 Introduction

This chapter aims to discuss and synthesise the main findings from this study. It will begin by summarising the key findings from both phases. The limitations and strengths of this study are then presented. How the findings relate to, support and extend other work in this field is subsequently explored. It will be acknowledged that there were contradictory findings and areas of uncertainty remain. To meet the aims and objectives of this study an engaged scholarship and participatory approach underpinned by the initial iterative phases of the UK MRC (2000; 2008) Framework for Development and Evaluation of Complex Interventions was followed. A reflection of the challenges and benefits of undertaking such an approach, including some significant ethical issues, will be included within this chapter.

8.2 Summary of the Findings

When the idea for this project was first conceived, the original aim was to develop interventions that would prepare and support carers who cared for patients receiving chemotherapy. As highlighted in Chapter 1, the idea arose from a conversation held with senior nurses in response to an increasing emphasis placed, in both policy and clinical practice guidelines (NICE 2004), on providing more support for cancer carers. However, these senior nurses were unsure how best their organisation could intervene to support carers in the acute cancer setting. Indeed carers' experiences and needs for support were not clearly understood.

The pre-clinical phase findings demonstrated that carers adopted important roles while supporting patients during chemotherapy. Although healthcare professionals acknowledged that carers were vital for ensuring the patient received their treatment safely, carers were not proactively prepared and their needs were frequently ignored by the service. When carers' supportive care needs were met, it depended on the actions of individual practitioners, usually nurses. Overall, it appeared that carers and healthcare professionals were divided by a 'no man's land'[10]. They were found to be 'disconnected' from each other mainly because of uncertainties and fears (Figure 17). A significant concern for both was undermining the patient. Indeed, most practitioners in this study stated their focus and duty of care was foremost to the

---

[10] This term usually refers to the strip of wasteland, which was left unoccupied and unused by soldiers, in World War I, who remained in their trenches uncertain how to proceed for fear of being killed.

patient. Yet, carers and healthcare professionals ultimately had the same goal. Both wanted the patient to be cared for effectively and safely to ensure the best possible outcome of treatment.

The findings, especially those from the carer interviews, revealed what helped carers the most were individual practitioners who were mindful of carers' roles and needs, had the ability to acknowledge and manage difficulties, and sign-post people when necessary to other sources of support (Worthington et al, 2013). These skilled practitioners, usually nurses, therefore, had an awareness of both the patients' and carers' situation. Yet, while many healthcare professionals when interviewed could articulate carers' roles and needs, most were found to have little 'carer awareness' in their interactions with patients and carers. Indeed, during observations few practitioners were seen to acknowledge or address those who came with the patient, and patients were rarely asked if they had support at home.

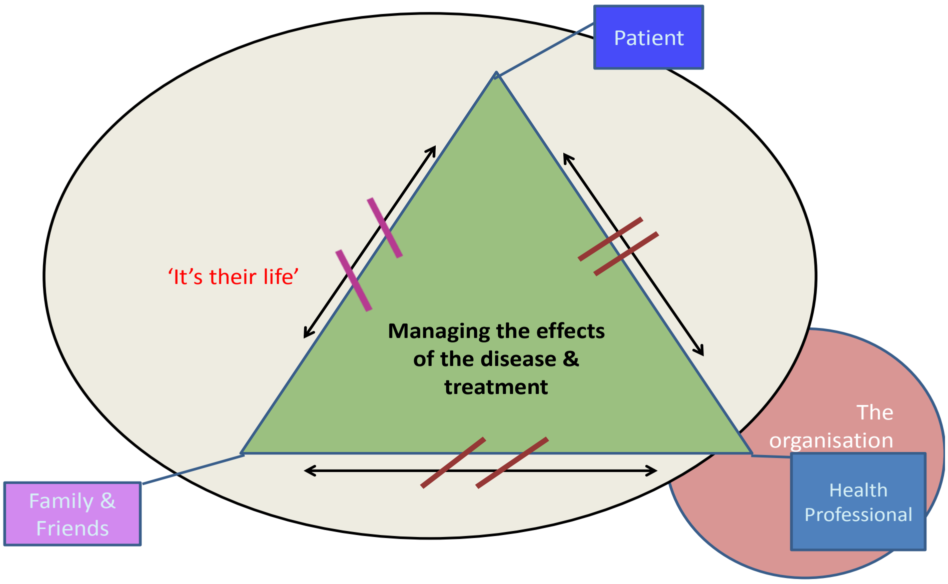
Figure 17: A Disconnected Model of Involvement

Adapted from Worthington and Rooney (2010)

In chapter 1 it was identified that a core underpinning principle of nursing (especially in the cancer domain) is to provide collaborative supportive care to not only patients but also their families and carers (NMC, 2008; NICE 2004). The puzzle at the beginning of this research was why there appeared to be a gap between this espoused nursing value and the actions of clinicians in practice. Furthermore, a key review finding (Chapter 2) was previously developed research-based interventions for meeting cancer carers' needs had failed to be translated into clinical practice, why this occurred was not clear. However, the review and fieldwork findings also established that until now healthcare professionals' needs for effectively supporting carers were a neglected area in practice, policy and research.

Healthcare professionals were found to endure unrelenting workloads and worked within complex and constantly evolving clinical settings. Practitioners acknowledged that genuinely involving carers in these environments was difficult. They identified numerous barriers, which prevented carers' needs being addressed and supported in this setting (depicted in Figure 18 below). Obstacles to supporting carers were apparent at every level of the healthcare system and within organisational culture. Furthermore, a disconnected model of involvement was also found to exist within policy and professional guidance. In many documents carers were frequently included as an 'add-on' rather than an essential component of patient care. It was, therefore, not surprising that healthcare professionals were often uncertain and confused about how best to involve carers in patients' care. Consequently, the focus of this work shifted (as the study evolved) towards exploring and meeting the needs of healthcare professionals rather than focusing only on the supportive care needs of carers.

Figure 18: Barriers to Involving and Communicating with Carers



An important finding is that every patient and carer situation is different. This required practitioners to be adaptable and capable of identifying and managing peoples' individual needs. At the same time it was found to be important to induce a sense of security by steering both patients and carers through, what for them, was a very uncertain and often distressing time. Yet, illuminatingly, healthcare professionals revealed that involving carers had a potential '*to open a can of worms*'. Initiating the need to acknowledge ethical predicaments, social problems and/or emotionally distressing issues for which practitioners perceived they were ill-prepared and had little resources to manage within the current constraints of the service. Involving carers required staff to have a difficult conversation. Thus, many practitioners were reluctant to engage with patients' and carers' emotional needs and would use strategies to avoid doing so. This was primarily due to their perceptions of insufficient skills and confidence, particularly for managing different expectations, difficult emotions, complex information and problematic family dynamics and having little time to do so. Practitioners chose instead to focus on the technical and practical, '*tick-box'* assessments and provide information, rather than engage with what was thematically described as 'managing the emotions in the room'. Paradoxically, these actions added to healthcare professionals' personal frustrations and dissatisfaction with their work and how patients were currently cared for.

During this study other important concerns revealed themselves. As highlighted above, carers were found to perform extremely important roles at home to ensure that patients were not only safe but also able to cope with treatment practically, physically and emotionally. However, the findings demonstrated practitioners, who were not 'carer aware' or felt unable to talk to patients about their support at home, frequently failed to identify patients who were alone and isolated. This had serious implications because these patients were potentially vulnerable, at risk of becoming ill at home with no-one to help them.

In the modelling phase, an action research approach was adopted, providing an opportunity to explore the feasibility of some of the strategies previously identified by healthcare professionals in the formal and informal interviews (Table 20, section 6.6). The participants were mainly nurses. The fieldwork findings were shared in two workshops, one on each site. Here the participants concurred with the findings and added further insights. A number of important issues were revealed. Firstly the nurses expressed a great desire to determine 'when was good, good enough?' The second issue was the need for nurses when engaging with carers to also 'feel safe', if they were to induce a sense of safety in others. A principle aim of the modelling phase was to find ways to do this. What also needed to be determined was how nurses could be enabled, to become less reticent, more confident and develop capabilities to manage the complexities of interactions between patients, carers and themselves within the current constraints of the service.

After the workshops, participatory meetings and work ensued. Two simple tools, a 'fridge magnet' and a 'support notebook', were developed by nurses with much input from the carer advisory group. While these tools appeared simple they had significant and multifaceted aims. These tools were to help nurses provide a straightforward message to both patients and carers that the carer was included, had 'permission' to ask questions and was welcome to contact the units if they required advice. The 'support notebook' also contained what participants considered to be the most vital generic information carers needed to have when caring for the patient at home. This information outlined what side-effects to monitor for and what do if a patient became unwell. It also provided the questions doctors and nurses would ask when patients had their appointments.

The participatory meetings or as the nurses described them '*evaluation meetings'* revealed different but illuminating findings. In Site 1 the nurses acknowledged they had used these tools as 'props'. Initially the nurses at Site 2 did not use the tools. There were many reasons (to be discussed later in the chapter). However, by providing time and space to listen to the nurses' views and concerns, while also facilitating an opportunity to share and learn from each other, enabled these nurses to experiment with the tools and explore how pre-chemotherapy consultations could be conducted in a more person-centred way. Subsequently, the nurses on both sites reported that the tools had been well received by most patients and carers and other members of the MDT. This then gave them the confidence to keep using the tools and try out different strategies. All the nurse participants (and some of the doctors) expressed how much they had valued having their concerns genuinely acknowledged and having opportunities to share with each other different strategies to help them manage this aspect of supportive care.

Overall the findings revealed that when 'safe spaces' in conjunction with critical but sensitive facilitation, nurses themselves could find solutions to overcome some of the challenges they experienced, by learning from and supporting each other. Coming together in groups enabled nurses to reconnect with their personal values about what was important and develop a shared understanding of the type of healthcare service they wanted to provide. They were encouraged and facilitated to get off the '*hamster wheel of busyness'* to stop and reflect upon what they did and how they were doing it (McCormack and Manley, 2004, p. 88). In doing so participants identified and initiated actions, for example, they developed tools for carers, made changes to the clinical environment, ordered new chairs for visitors, furniture and televisions for the waiting rooms, started to adopt a person-centred approach to pre-chemotherapy consultations, some nursing participants attended training courses in leadership and communication skills. As the research came to an end plans were being instigated to send all nursing and support staff working in this setting for communications skills training (SAGE & THYME, Connolly et al, 2010) and to write a shared philosophy, which incorporated the importance of involving and supporting carers.

The tools, the fridge magnet and support notebook, developed in the modelling phase, were not, therefore, the overall solution to problems identified in this study. They provided only a small but potentially very useful component of an intervention to enable healthcare professionals to prepare and enhance the support for carers. It will be argued later in this chapter that policy and service priorities for providing better support for carers are in danger of becoming what Grint (2008) describes as a 'wicked problem' . This is because there are, as this study has found, many complex problems, uncertainties and barriers in clinical practice, which can prevent healthcare professionals addressing carers' needs. It is acknowledged that there are no discrete easy solutions, such as the tools developed in this study, for these problems. What needs to be recognised in healthcare service organisations, and by healthcare professionals and researchers, is that while some problems require technical action, many others are complex requiring many innovative solutions involving all who have a stake in the problem. It should be noted that I used the term 'enable' quite deliberately in this study. Collins (2014, p. 5) defines enablement as '*the degree to which people feel supported to develop their own unique range of capabilities'*.

The methodological approach followed in this study became the key intervention which enabled those who participated in this study to begin a small but significant shift in their attitudes and behaviours. Undoubtedly this research raised awareness of carers' needs across the service and enabled some staff (especially CDU nurses) to change aspects of their practice and clinical environment. Creating safe spaces was vital as nurses were able to explore ways in which they could balance the important technical aspects of their work with a more person-centred approach. They were encouraged to 'reflect on practice' this helped these nurses to begin 'reflecting in practice' (Schon, 1991; Rolfe, 2011). However, without continuous organisational support it is highly likely that many of the changes initiated in this research will not become embedded into normal, routine practice. Other strategies, including training and educational initiatives, and integrating a whole systems transformatory approach are needed (e.g. unifying policy, the organisation and multi-disciplinary team) to enable healthcare professionals to address this important aspect of supportive care.

8.3 Limitations and Strengths

The methodological approach taken in this study created benefits and challenges. There were limitations, which could potentially impact on the credibility and robustness of the findings. Tellingly, many of the challenges reflect the limitations or challenges nurses acknowledged or were observed having in their work.

As with most research where qualitative and action research methods are used caution must be applied before generalising more widely from the findings. The most obvious limitation is that it was a small study conducted within a cancer service in just one NHS Trust. A general hospital, which at the time this research was conducted was going through many difficulties idiosyncratic to that particular organisation. Therefore, the problems identified in this study and the solutions for these cannot be automatically extrapolated to all clinical settings.

The limitations of the review of reviews were described in section 2.8.2. However, another important limitation became apparent during the course of this study. Focusing only on reviews of literature from the acute cancer setting excluded the possibility of exploring how practitioners and researchers from other backgrounds had approached this subject. It was for this reason that the views of healthcare professionals working in different sectors, for example, palliative and mental healthcare, were sought. The informal caregiving literature from other disciplines has also been explored and will be drawn upon during this chapter.

The terminology used to describe people who supported patients through treatment could be viewed as a limitation. The term ‘carer’ was originally used for pragmatic reasons (section 1.5). However, what I did not anticipate was how uncomfortable it would be to approach and ask patients about their carers. Indeed many patients initially rejected the term. They would say they did not have a carer nor did they need caring for. Using the term carer was potentially introducing a concept that they had not considered before. I was introducing the notion that they would need to be cared for at home, that their disease impacted on other people and they too might need support. Thomas et al (2001) experienced similar dilemmas and as they did I needed to spend a considerable amount of time sensitively explaining the terminology and purpose of the study to patients. This paid dividends. Most patients would recognise the need for conducting this research and would offer valuable insights (or volunteer their carers). Some patients, while recognising that this research was essential, acknowledged they did not have a carer or were isolated from family or friends. For some, this did evoke an emotional response and this required sensitive management.

Recruitment of carers for interview was dependent on the willingness of both the patient and the carer to be involved. This process added another level of complexity. Some patients, because of family dynamics, may have identified the person they felt they should nominate rather than the person who was in reality supporting them. It was for this reason, in the case of two patients, that both the daughter and partner were interviewed. Patients were gate-keepers and some did essentially prevent access to those who supported them at home.

Although every effort was made, I was unable to access and interview carers of patients from Black and minority ethnic groups (BME). It is not clear why this occurred. Eggly et al (2013) explored, through observation and interviews, patients’, their companions’ and oncologists’ experiences of consultations. They found it difficult to recruit BME patients (mostly Black African) because recruitment depended on who came to the appointments. Unlike Caucasian patients who usually came to medical meetings with someone these patients were often unaccompanied. Their findings resonate with those of the evaluation meeting held in Site 1. A cancer unit, which provides services to an ethnically diverse population, many of whom were Black African; yet the nurses had recognised that this patient group frequently attended appointments alone, carers were therefore less accessible. These patients were also reticent about accepting the developed tools.

When using participatory observation as a method, it is important that researchers should avoid, as much as possible, disrupting the naturalness of the research settings (Watson et al, 2010). My position as a nurse researcher undoubtedly impacted on the work of the staff and unit. Although surprisingly not in the way one might expect, I anticipated there might be a ‘Hawthorne and Observer Effect’, whereby my watchful role and the introduction of the carer concept would change the way the healthcare professionals behaved and interacted with carers, or alternatively carers approached staff (Pope and Mays, 2006; Mulhall, 2003). However, during observations healthcare professionals rarely acknowledged the person accompanying the patient. My presence did initiate discussions between healthcare professionals with both myself and each other. They began to reflect on and question their practice. These discussions were not only focused on how they supported carers but also how they conducted consultations.

The pre-clinical phase had a dual purpose, firstly to establish what the problems were and secondly to generate participation (Waterman et al, 2001). Throughout this phase strategies were used to build rapport and trusting relationships with the participants. Findings and questions were shared with practitioners. This required a careful balance of trying to remain objective while seeking participants’ perspectives and involvement (Stringer, 2007). In this phase it was also important to avoid introducing change. The nature and scope of the problems needed to be understood from many perspectives before any change was implemented. I was aware how detrimental it could be, both to the emotional welfare of the participants and integrity of the research, if change was introduced before we had this understanding. Waterman et al (2001) questions whether using qualitative research data collection methods in action research prevents practitioners and service users from being truly involved in the decision-making process and having ownership of the research. As can be seen in Chapter 7, there were tensions. While democracy for all participants is an aim of action research it is dubious whether this is achievable; especially when research is conducted in hierarchical and constantly evolving organisations (Meyer, 1993a). However, from the start of the project it was constantly reiterated to participants and stakeholders that I did not have the answers. Therefore, I was asking for their help, to formulate the problems and think of solutions to address them. My fundamental role, although at times challenging, was not to impose my views on participants but to listen to theirs.

Denscombe (2010) suggests '*the key instrument of participation methods is the researcher as a person*'. As such, the findings inevitably become an interpretation of what the researcher has observed or heard and are, therefore, open to subjectivity and bias. However, an important strength of this work is that the analysed findings were shared with staff participants and stakeholders, a process described as 'member checking' (Houghton et al 2013; Stringer, 2007). This was to ensure a credible and reasonably truthful account had been captured. Although the findings were not shared with patient and carer participants they were reflected upon with members of both the project and carer advisory group. This was to confirm the findings resonated with their experiences of being either a patient or a carer.

There is no magical formula to help qualitative researchers identify an ideal number for the amount of interviews that should be conducted (Baker and Edwards, 2012). While it is acknowledged that the interview sample sizes may have limited generalisability, an important strength of this work was that data was collected from various sources through prolonged engagement and persistent observation. Notably the informal conversations held with participants during observations, especially patients, elucidated more insights than some of the formal interviews. Recruitment of participants for the purpose of interview, therefore, ceased at the point of data saturation. Larger interview sample sizes would have provided more data but not necessarily more insights (Mason, 2012).

In the modelling phase action research methods were adopted. Ideally a number of cycles of planning, acting, observing and reflecting should be conducted (Meyer, 2010; Stringer 2007). The aim of which is to embed the introduced changes into everyday practice. A limitation of the modelling phase was that only two cycles were conducted before the research project came to an end. The support notebook and fridge magnets appeared to be valued by staff, patients and carers, and were relatively inexpensive to produce. However, without continued research and further organisational/financial support their sustained use is questionable. It is highly likely that many of the practitioners, although not all, will revert to their previous ways of working with carers. In this phase as a result of financial, organisational and time constraints, some of the ideas for developing learning opportunities and educational tools were also blocked.

Different members of the MDT did not become involved with the research and this was a limitation. Many doctors while verbally supportive were difficult to engage. Some were patronising, two doctors were openly hostile and critical, while the majority although pleasant treated the study with indifference. Their comments and behaviour at times demonstrated that they viewed me as a nurse doing ‘nice’ but not vital research. Overall, nurses and AHPs were very supportive of this research and thought it was important. A particular strength was the problems became a puzzle many of the nurses wanted to help solve.

In section 4.6 it was described that I held neither an ‘insider’ nor ‘outsider’ position within the research site. However, in reality I oscillated between the two throughout. As a nurse with ‘insider’ knowledge I was able to quickly grasp and understand events as they occurred and question when differences between observed practices and the ideologies of practice were apparent. However, I made assumptions based on my nursing knowledge and sometimes missed the obvious. The visitors’ chairs were an example of this (Figure 10). It took a while before I recognised what the uncomfortable chairs may symbolise to visitors. However, as an outsider I was frequently naïve to some of the established practices and relationships within the units.

Hockley’s (2013) experiences of being an outsider, while undertaking an action research study in a nursing home, resonate. As an expert in palliative care Hockley (2013, p.22) found the difference between ‘power’ (having the ability to do something) and ‘authority’ (having the right to do something) particularly difficult to reconcile. Similar to Hockley (2013) in the outsider role I had ‘power’ as a perceived expert but little authority. A precarious position because this work relied upon the goodwill of many participants who could have perceived me as a threat (Meyer, 1993a). This perhaps provides one explanation for why some practitioners did not engage or fully participate. Challenges also occurred when I thought patient care (although fortunately not safety) might have been breached. In most instances I avoided intervening, as I could have been viewed as judging the practitioners and as an ‘expert’ I knew better. My role was to understand the current realities of practice from the practitioners’ perspectives. This does not mean that practices were not challenged. Providing feedback needed to be at an appropriate time when it was considered psychologically safe for the participants to hear, which was also not without its difficulties.

It is difficult to wholly portray the incredibly supportive and reciprocal nature of the relationships that evolved and have been established with both healthcare professionals and carers during this study. Building relationships and creating supportive environments required time and commitment (Okumus et al, 2007). However, involving others undoubtedly strengthened the methods and gave credence to the findings. Establishing a carer advisory group was invaluable. Members became close critical allies, providing motivation, enthusiasm and moral guidance. They offered unique insights into the challenges of supporting patients, bestowing what one carer member described as knowledge from the ‘*university of the flipping obvious*’. Although, at times not so obvious to either myself or the staff participants.

Underpinning this work with change management and implementation theories strengthened this research. An important aspect in the development of research-based interventions, which aim to be beneficial and adopted, is gaining an understanding of the problems from the perspectives of all those the intervention aims to help (Van de Ven, 2007). This study has extended the work in this field by comprehensively exploring the perspectives, experiences and needs of healthcare professionals. Unquestionably, using a participatory approach and genuinely engaging with practitioners, while challenging, is a key strength of this study. It enabled a deeper and more meaningful insight into this very complex aspect of supportive cancer care.

8.4 'The Hamster Wheel of Busyness'

When developing research-based interventions, which inevitably endeavour to change practice or behaviours it is important to gain an understanding of the organisation and its culture, values and beliefs. The organisation was one of turbulence, undergoing relentless and unpredictable re-organisational change; as a consequence the healthcare professionals were very demoralised. Fox et al (2007) when discussing the management of change in the NHS describe it as thus,

> '*We trained hard, but it seemed that every time we were beginning to form into a team we would be reorganised. I was to learn later in life that we tend to meet any new situation by re-organising, and a wonderful method it can be for creating the illusion of progress, while producing confusion, inefficiency and demoralisation'*. Caius Petronius AD 66, (cited by Fox et al, 2007, p.43).

This encapsulates perfectly the situation staff at the research sites were experiencing. Practitioners needed to keep their knowledge of treatment and care up-to date, while meeting the demands of ever increasing patient numbers, audit and peer-review measures, in a context of perpetual organisational change. At both sites the environment was found to be technically complex, task orientated and medically driven. Staff described these environments, as others have done, as 'relentless hamster wheels' (McCormack and Manley, 2004, p. 88). In the persistent busyness of the environments, time and resources, including drawing upon the expertise within the teams, were found to be used either inefficiently or not at all. In agreement with others, I initially thematically described the environments as '*factory lines'* (Maben et al, 2010; Goodrich and Cornwell, 2008; Porter 2002). As this study evolved it became apparent that this description was neither fair nor entirely accurate. It was an organisation perceived by staff to be focused on budgets and targets rather than patients and as the NPSA (2013, p. 10) point out *'when the pursuit of targets becomes for whatever reason, the overriding priority, the people who work in that system may focus too narrowly'.* However, paradoxically none of the patients or carers reported being impacted by the continuous organisational changes. Indeed most patients reported having a good patient experience and this was because most of the staff worked very hard to hide the imperfections of the service.

All the healthcare professionals I encountered during this study were dedicated and hardworking. Therefore, I found it extremely difficult to hear their distress, despondency and guilt because they perceived the care they provided within the systems they worked was unsatisfactory. They were enmeshed within the challenges of significant organisational change, financial deficits and feared for their jobs. The leadership team, those working at a strategic level, were in the words of some participants, '*working very lean*' and focused on '*fire-fighting*'. No one was really listening to the clincial staff. These findings undoubtedly impacted on and influenced this research. Indeed, there were times when I found it difficult to comprehend how such an overburdened service and its staff could genuinely provide person-centered care and support to patients, let alone carers.

8.4.1 Being Good Enough

To begin the interviews I asked healthcare professionals, as a way of helping them relax, to talk about their roles and whether they liked their work. These questions unwittingly produced some illuminating but conflicted findings in relation to carers. The practitioners, especially nurses, used highly emotive terms to describe how they felt about their work. Although, practitioners gained great satisfaction from their roles, all who were interviewed described feeling frustrated and constrained by the current situation and politics of the organisation. The nurse participants described '*knowing the patient*' and '*being there*' for them as the most valued and satisfying aspect of their work. In this study the staff did indeed appear to know the patient and most patients expressed '*they are lovely here, they know me*'. In reality little systematic, holistic nursing assessment of patients' needs occurred. Therefore, knowing the patient was potentially at a superficial level. This became evident during informal conversations when patients acknowledged that they did not have a person supporting them at home. The CDU nurses were often unaware of these patients' social circumstances.

However, nurses in this study aspired to have a therapeutic relationship with their patients, they espoused this role. Bridges et al's (2013) insightful meta-ethnography explored how nurses experience and characterise the therapeutic relationships they have with patients and their families. They found that nurses perceived the therapeutic relationship as one which has the '*potential to support informed decision making and treatment response assessment to give the medium through which tailored care, comfort and support is provided; to guide and support patient decision-making; to reconcile differing perspectives between patient, family and professionals; to act as patient advocate' (*Bridges et al, 2013, p. 763). Interestingly, this description provides clues to the underlying tensions nurses may have trying to meet the needs of carers. However, as Bridges et al (2013) also established, the findings revealed that nurses described feeling constantly guilty and frustrated, as they often perceived they were failing to meet their own expectations of the therapeutic relationship, because of the relentless workload.

Linsley and Carrol (2012, p.45) contend that an important component of the therapeutic relationship is an awareness of the boundaries and limits of the professional role. The notion of when is ‘good, good enough’ was a recurring theme throughout the research but particularly in the workshops. Allan’s (2001) findings again have relevance here. She described being confused, as I have been, by the patients’ and nurses’ descriptions of their relationships with each other. They described to her in interviews, what appeared to be ‘*fantasies*’ of the ideal nurse. Allan (2001) reports being mystified when patients described ‘*feeling known’* by the staff, because she observed nurses using tactics to avoid engaging with patients on an emotional level. Equally, patients also revealed to Allan (2001) that they had not wanted to share their concerns or distress about their fertility problems with the nurses. Similar to most patients and carers in this study, patients did not seek to have an intense emotional attachment with the nurses. Yet, this is what the nurses espoused. Patients recognised that the nurses were concerned about their welfare and competently looked after them. This in reality was good enough for the patient. Being ‘*good enough’* was described by Allan (2001, p.56) as a nurse who rather than seeking to have a deep emotional connection with the patient sought instead to have an ‘*emotional awareness’* and who could intervene to manage emotional distress if required.

The findings in this study indicated that nurses had some anxieties about carers. They perceived that preparing and supporting carers in the CDU setting would create yet more demands and draw upon reserves they did not have. The nurses needed support to rebalance their concerns and ‘fantasies’ of the involvement of carers. They also needed to understand and appreciate what they did well because patients were well cared for while they were in the units. However, I would argue that in terms of supporting carers, ‘good enough’ is being aware and mindful of carers’ roles and needs, have the ability to acknowledge and manage difficulties and sign-post when necessary to other sources of support.

8.5 Formulating the Problems: Carers

These next sections will discuss carers’ roles and needs for support. As highlighted above one of the key problems, which prevented healthcare professionals from providing support, was a fear that carers would need more from them than they could provide. Yet, this appeared not to be the case. Indeed, carers seemingly wanted very little from the service, which cared for the patient.

8.5.1 Carers' Roles

Carers were found to perform, over long periods of time (usually more than six months), numerous essential roles. The findings, from the observations and interviews, clearly support the work of others in this field as outlined in the review of reviews (section 2.6). Similar to Ockerby et al's (2012) findings, carers' main tasks included providing practical help and meals, emotional support and companionship while patients recovered during chemotherapy cycles at home. Carers worked hard to ensure that patients were not only physically safe at home, but were also emotionally safe during the treatment phase. Carers maintained normality (Thomas et al, 2001). Supporting patients to carry on as much as possible in their usual life and providing respite from the realities of the disease and treatment.

Importantly carers acted to ensure patients received the best possible care from the service. While healthcare professionals described a caregiving role of 'complainer', carers viewed this as an advocacy role. As King et al (2006) found, carers ensured continuity of care by chasing appointments and navigating complex service pathways. Observations of appointment and treatment visits revealed other vital caregiving tasks. Carers were a personal assistant and a recorder of information. Patients and healthcare professionals believed that it was extremely useful to have carers in meetings to act as a 'pair of ears and eyes'. Similar to the work of Hubbard et al (2010) and Dubenske et al (2010) findings demonstrated that carers performed a very important role enabling patients to make decisions about treatment. During consultations carers sometimes acted as conduit for information from patient to practitioners and vice-versa. In these meetings they, rather than the healthcare professionals, were the key providers of emotional support.

8.5.2 Carers' Challenges

Carers while performing these roles experienced numerous challenges (section 5.14). A significant problem was they were not proactively prepared at the beginning of the treatment trajectory. While there appeared to be a professional expectation that carers would support patients, their contribution was not acknowledged by providers. Carers were not told that patients would need their help or what this might comprise. Therefore, carers and patients did not appear to fully appreciate how critical the carer role was in the patients' treatment experience. Their assumed roles required a level of understanding and knowledge, which was often novel to carers. Unprepared and uninvolved, carers reported having feelings of great uncertainty and insecurity. Comparable to Stenberg et al's (2012) findings the most challenging aspect for carers was living with uncertainty. Carers were in an ambiguous place. As Thomas et al (2001) found, carers reported they often experienced uncertainty about, if, how and when they would be 'allowed' by healthcare professionals to participate in medical encounters.

Indeed, as described by some practitioner participants, '*they walked on egg-shells'*. In this study it was found they required permission to be involved, not only from healthcare professionals but also from the patients.

It is well recognised that receiving a cancer diagnosis is a significant and catastrophic event for patients and their families (Taylor et al, 2011; Plant, 2008; Epstein and Street, 2007). It initiates an intense period of change in people's lives, evoking fear and distress, regardless of whether the prognosis is good (Brennan, 2004). Although survival rates continue to improve, cancer remains an unpredictable disease. All the patients and their families reported feeling constantly uncertain about the future. Patients will inevitably feel out of control and powerless. Adapting to this change and regaining a sense of control, for many patients' means trying to hold on to whatever they can, to maintain the status quo (Brennan, 2004). Pertinently, Miller (1995) suggests that people will use two approaches, either 'monitoring' or 'blunting', to cope with cancer. 'Monitors' are those who actively seek information and want to be involved in the decisions about treatment and care. Many patients in this study were found to be 'blunters'. They preferred to stay in the present and actively avoided threatening information. This was extremely challenging for carers, many of whom adopted a monitor role. These different coping styles essentially prevented some carers from receiving timely information and support. Many of the healthcare professionals and carers reported shared tensions created by their obligation to respect the autonomy and wishes of the patient. Subsequently, this led to carers feeling uncertain about when to step in and when to stand back, especially with patients who while functionally independent still required high levels of emotional support.

Carers reported significant challenges when patients experienced side-effects, which they believed warranted professional advice and management. However, they were prevented by the patient from contacting the service. While most carers respected the patient's wishes, it created conflict and anxiety. Patients' reported that they wanted to avoid bothering busy hospital staff and long waits in A&E departments. They did not wish to be admitted for treatment. As McKenzie et al (2007) found patients could delay seeking professional advice for adverse effects for a significant amount of time (two to seven days). Carers, in this study, reported not knowing what to do in these situations. It placed carers in a precarious situation, realising that the patient could have a serious life-threatening problem. Yet, they felt powerless to do anything about it.

Carers described, as others have found, the emotional support they provided to patients as a vital but difficult role (Deshields et al, 2010; Ream et al, 2010). Most patients thought they managed their own emotional well-being and expressed a great need to hide their fears to protect others. Yet, carers were found, as others report, to frequently struggle with and know how best to manage the patients' emotions, while concealing their own (Resendes and McCorkle, 2006; Couper et al, 2006; Kinnane and Milne, 2010; Ussher et al, 2009). This left carers emotionally exhausted. Thomas et al (2002) makes the connection between the carers' work of managing the patients' emotions and their own, with the concept of emotional labour. A term coined by Hochschild (1983, p.7), which she defined as '*this labour requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others – in this case, the sense of being cared for in a convivial and safe place*'. Previously considered to be women's work and in the realm of female carers (James, 1992; Gray 2009). In this study, as Thomas et al (2002) found, both males and females engaged with difficult emotional work.

Many studies have reported that a lack of adequate information from healthcare professionals creates significant challenges for carers (Thomas et al, 2001; Adams et al, 2009; Resendes and McCorkle, 2006). Paradoxically, in this study, comparable to Ream et al (2010), carers reported being overwhelmed by verbal and written information (although predominately provided to patients). Nevertheless, they remained uncertain about what they should expect, how to plan for the future, how to manage their lives, how services were delivered, who they could contact for advice and what side-effects to monitor for, how to manage medication regimens and what they personally should do to help the patient. The challenge for carers was making sense of the information and trying to decipher what was important and pertinent to their situation.

8.5.3 Carers' Needs

Carers constantly reiterated throughout the study that their most important need was to ensure the patient was well-cared for and safe. Similar to the findings of a study undertaken by Kayser et al (2007) most of the carers viewed the patients' disease as a '*We-Disease*'. Patients in this study were found overall to be well cared for within the CDUs by very knowledgeable and caring healthcare professionals. Adverse events in the clinical settings, allergic reactions for example, were swiftly managed.

There were, however, contradictory findings. Very few carers in this study reported wanting support from the service to help them manage the emotional impact of the disease. Most carers preferred to seek support from their own social support networks. These findings contradict previous recommendations that psychological interventions should be provided to cancer carers (Ussher et al, 2009; Northouse et al, 2012). Moreover, none of the carers involved in this study, including members of the carer advisory group, actually viewed the acute cancer service as being there for their needs. The practitioners and the service belonged to the patients.

However, the findings revealed that patients not only needed to 'be safe' while receiving treatment, patient and carers also needed to 'feel safe' when at home. As highlighted above, an important caregiving role was to ensure patients felt safe. Yet, carers reported that they often felt very insecure especially in the initial stages of the diagnostic and treatment process and when adverse events occurred and/or at weekends. Conversely, patients felt very 'unsafe' when treatment ended, while carers acknowledged feeling relieved it was over. However, for a few carers their sense of security certainly increased when their roles had been acknowledged by a health professional, usually a CNS. These practitioners provided carers with pertinent and timely information, which enabled them to support the patient. When patients were at home, carers also felt more secure when they were confident that a knowledgeable and capable practitioner could be easily accessed.

8.5.4 Interventions: When, What and How to Help Carers?

Carers and healthcare professionals universally agreed that it was important to have carers present at the important meetings, for example pre-treatment and on-treatment consultations. However, acknowledging and welcoming carers in every patient interaction was deemed by carers as an extremely important intervention healthcare professionals should always carry out. Similar to Speice et al (2000) who explored patients' perspectives of the carer role, the findings revealed patients and carers greatly valued healthcare professionals using simple strategies and actions to include the carer. These actions included inviting carers into the consultation room, asking for their names, encouraging them to write notes and providing contact details. Carers in this study were frequently observed writing notes in consultations. Some carers acknowledged that they wrote everything down, as an aide memoire. It was these findings that originally instigated the idea for the support notebook.

Timely interactions with a health professional were deemed by carers to be the most supportive intervention. Comparable to the findings of Gilbert et al's (2010) study, which investigated carers' perceptions of positive and negative interactions with mental healthcare professionals, carers valued practitioners who welcomed and involved them; who were aware that carers needed relevant information and would take time to help them understand it. Importantly, carers greatly appreciated when the health professional recognised their life was currently difficult and they were receptive to hearing their concerns if that was needed. Sometimes just being able to talk to a professional who understood and could empathise was deemed important.

An important finding is that there were resources outside of the patients' treatment service, which could provide emotional support, practical and financial assistance to the patients' carers.

The carers' GP, Macmillan Cancer Support and other cancer voluntary organisations (who have produced information leaflets for carers), Citizens Advice Bureau (CAB) for financial guidance and the carers' own support networks. However, because carers were not acknowledged nor their needs assessed, it was rare that carers were signposted towards these resources by staff working in the acute cancer setting.

It was a puzzle. On the surface strategies healthcare professionals and the service could use to intervene appeared relatively simple. Asking some basic questions, see table below, could prove to be very helpful and potentially prevent problems and complaints. Yet, most healthcare professionals perceived that asking these questions would be exceptionally challenging.

Table 24: Questions That Should Be Asked

The Person	**Questions**
The Patient	• What do you understand about the treatment? • What concerns do you have? • What do you need to help you manage at home? • Who and where do you get support from? • Is it acceptable to discuss care and share information with the identified support person?
The Carer	• Hello …. Who are you? • How are you coping? • What concerns do you have? • What do you need to help you?

8.6 Formulating the Problems: Healthcare Professionals

It is clear from the findings that there were inconsistencies, relating to carers, between healthcare professionals' knowledge and aspirations and their actions in practice. Healthcare professionals stated they recognised the importance of acknowledging and welcoming carers when they attended patient appointments. Paradoxically very few were observed doing this. Most healthcare professionals had a cognitive understanding of carers' roles (section 5.14). Indeed many had a better understanding of carers' challenges and needs than carers and patients. Yet, few were found to proactively involve carers in this setting.

Walker and Dewar's (2001) study investigating the facilitation of carers' involvement in the mental health setting similarly revealed that the extent carers were involved depended largely on the practice of individual practitioners. These practitioners were able to see the 'people behind the patient'. However, most healthcare professionals were observed to have little '*carer awareness'*. This concept is defined as staff '*being aware of and welcomes the valuable contribution carers can make and be mindful of carers' own needs'* (Worthington et al, 2013, p.9). As previously recognised in the NICE (2004) guidelines, healthcare professionals acknowledged that when carers were offered support from the service it was usually as result of a crisis when patients became extremely unwell.

As previously highlighted healthcare professionals described numerous challenges which they perceived prevented carers from receiving support from them personally and the service (section 6.2). Some of the barriers reported in this study were perhaps unsurprising and included the busyness of the units, the constraints of maintaining patient confidentiality, lack of professional guidelines, time, finances, resources and organisational support. Some of these difficulties were supported, albeit only briefly, in a recently published review by Northouse et al (2012). However, as the study evolved further challenges were revealed, it was complex. Yet the experiences and needs of healthcare professionals in this aspect of care until now have been a neglected area in practice and research. This is likely to change. Since starting this study there is now a plethora of evidence which clearly demonstrates that research-based interventions aimed at supporting cancer carers have failed to be translated into practice (Ussher et al, 2009; Lambert et al, 2012; Northouse, 2010, 2012; Romito et al, 2013). With increasing attention being paid to the implementation of research (section 3.10) it is highly probable that other researchers, funders and policy makers will also question why this is the case.

8.6.1 Patient Centred Care: Conflicts and Uncertainties for Staff

Quality in healthcare is currently determined by a number of factors and includes patient experience, safety and outcomes (NHS, 2008; NPSA, 2013). It is now generally accepted that a good patient experience depends on healthcare services placing patients in the centre of their care (Manley et al, 2011) or as the King's Fund have depicted '*seeing the person in the patient*' (Goodrich and Cornwell, 2008). Patient-centred care is defined by the Institute of Medicine (2001) *as 'providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions'.* Interestingly, as highlighted previously, in reality the people who did most of this patient-centred work were the carers not healthcare professionals. Carers had a key role helping patients make decisions about their treatments, yet their involvement was not acknowledged.

The Institute of Medicine (2001) and the King's Fund (Goodrich and Cornwell, 2008) clearly state that a core dimension of patient-centred care includes involving patients' family and carers. As previously explored, the patients' experience is inextricably linked with how their families and carers experience both the disease and the service (King et al, 2006; Parker et al, 2011). However, the findings demonstrated that healthcare professionals whose acknowledged duty of care was first and foremost to the patient had conflicted and confused views towards involving carers. This was because they did not necessarily perceive supporting carers to be patient-centred. The ideology of patient-centred care can be at odds with that of carer involvement. It is very difficult to reconcile the two if, for example, the patient as an autonomous person does not want their family involved.

Although healthcare services should strive to provide patient-centred care, a further problem for healthcare professionals were the reported tensions between delivering patient-centred care with meeting the needs of the service and providing safe treatment. They recognised that there were situations when they needed to clearly identify to patients what the expectations of the service were to ensure patients were safe. Yet, some acknowledged they were sometimes reluctant to explicitly tell patients what they needed to do. This left patients and carers often uncertain about what they should do. While practitioners were also uncertain how best to manage situations when patients did not follow advice.

8.6.2 Is it Patient Centred Care or Person-Centred Care?

Although the term person-centred care has been around for decades it now appears to be superseding the term patient-centred care within policy and the literature (The Health Foundation, 2014). Carl Rogers has been credited with introducing the term 'person-centeredness' in the 1950's (The Health Foundation, 2014). He argued that a core component of person-centred care was that practitioners needed to demonstrate 'unconditional positive regard' and empathy to their clients (Rogers, 1961). Although these attributes remain central to person-centred care ideology the term has continued to evolve and is often used interchangeably with patient-centred care. However, there has been disagreement over the use of the terms. Kitson et al (2012) for example, conducted a narrative review which aimed to identify how patient-centred and/or person-centred care was defined within the healthcare policy, medical and nursing literature (n= 60 papers). While they were unable to find a shared common definition, three core elements common to all healthcare disciplines were identified. These included *'patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered'* (Kitson et al, 2012, p.4). Kitson et al (2012) acknowledged that McCormack and MaCance's (2006) work made a significant contribution to the findings of their review. McCormack and McCance (2006) have argued that person-centred care within healthcare services can only flourish if the attributes of the nurse and the context of care (the environment) are considered along with the needs of the patients and their carers. Their work resonates with the findings of this study, which highlight that person-centred care is not only about being able to 'see the person in the patient' (Goodrich and Cornwell, 2008) but also the people behind the patients (carers) and the people who work within the system and deliver services (staff).

However, the findings of this research have demonstrated an uneasy juxtaposition between the aspirations of government policy and NHS organisation strategies (to provide more person-centred care) and the realities and tensions of clinical practice (The Health Foundation, 2014), where budgets and resources are being severely reduced. If healthcare professionals are to fulfil the current political and NHS rhetoric of person-centred care, which incorporates carers' needs, then they must have the practical transparent guidance, support and resources to do so. As Manley et al (2011) state *'achieving person-centred care consistently requires specific knowledge, skills and ways of working, a shared philosophy that is practised by the nursing team, an effective workplace culture and organisational support'.*

8.6.3 Carer Terminology

Another major barrier was the terminology used to describe those people who supported chemotherapy patients at home. Undeniably the term 'carer' has been a source of much debate with participants and advisors throughout this study. There are no universally agreed definitions or terms used to describe this role (Romito et al, 2013; Thomas et al 2002). While, most healthcare professionals acknowledged that 'carer' as a term did describe the roles people undertook when caring for someone who was having chemotherapy, they did not like the term. The family members who were interviewed undoubtedly had adopted the carer role, as defined by government policy, someone who *'spends a significant proportion of their life providing unpaid support to family or potentially friends' (*DH, 2008a, p.11). None of the interviewed carers had received a 'carer assessment' or were in receipt of benefits. This was an expected finding, because for most the carer role was a relatively new one. Additionally, the interviewed carers rarely viewed themselves as a carer. They did, however, recognise themselves as a key support person. Healthcare professionals had reservations about using the term with patients. They described similar dilemmas to those I had experienced when approaching patients about this study. It is for this reason that the participants and carer advisors chose to use the terms, '*family and friends'* and '*those who are supporting or caring for people undergoing chemotherapy'*, rather than carers on the support notebook. However, this is an area, which warrants further research and consensus within policy and practice because the terminology clearly creates obstacles and confusion.

8.6.4 Roles and Team Working

Healthcare professionals and carers identified problems because of poor continuity of care. This was related to uncertainties about professional roles, lack of teamwork and inadequate sharing of information between professionals (both internally and externally, for example, primary care). As King et al (2006) found, when these problems occurred, the implications for patients and their carers were devastating. It diminished their trust in the service and further increased their sense of insecurity and uncertainty.

Most of the participants recognised that all practitioners regardless of their professional background had a responsibility to support carers. The NICE (2004) guidelines for supportive care recommend that cancer services should have a designated person with overall responsibility, who will champion the needs of carers. Yet, no one in the service did this. However, the CNSs were identified by staff as having an overall responsibility for overseeing, co-ordinating and managing the supportive care provided to both patients and also their families within the service. NCAT (2010) emphasised these important roles require CNSs to have highly developed interpersonal skills, technical knowledge and empathetic understanding of the experiences of cancer patients. There is, therefore, a general assumption that CNSs will be able to provide supportive care throughout the patients' disease to both patients and their families (Sullivan, et al 2013). It is questionable whether CNSs can truly champion the needs of carers for a number of reasons.

CNSs were found to be over-burdened due to ever increasing patient numbers. Many held a case-load of 150 patients or more. The service was disease focused and medically led. While medics acknowledged their important role, many CNSs whose espoused role was to advocate on behalf of patients and their families rarely contributed nor were their opinions sought in formal multi-disciplinary meetings (MDMs). Their roles were mostly administrative. Information regarding patients was shared with doctors behind closed doors. Wright et al (2012) suggest that medical consultations require teamwork between nurses and doctors, with nurse-led assessment on psychosocial needs and doctor-led for disease related issues. Yet, consultations were not collaborative. The CNS role was to quietly hover waiting to see if they would need to intervene once the meeting was over. The supportive aspect of the CNSs' work with patients was consequently, largely invisible and appeared undervalued by other members of the MDT. As previously identified, trying to meet the different needs of both patients and carers could create tensions, especially when there were problematic family dynamics. It is, therefore, difficult to comprehend how CNSs could genuinely provide supportive care to both throughout the disease trajectory.

Many CNSs acknowledged having limited chemotherapy experience and knowledge. They had been recruited into their roles from surgical, not oncology, backgrounds. Hence, they had little insight into the experience of this treatment. As a result they frequently left patients' and carers' supportive care needs to be managed by the CDU staff during chemotherapy. Some patients and their carers did not appear to understand the CNS role. During the interviews it also became apparent that several carers and patients had received no CNS input at any point in the disease pathway. These findings were a cause for concern. Conversely, in some interviews it was very clear when patients and carers had been well supported by the patients' CNSs. These carers would contact the CNS rather than CDU nurses, regardless of the problem. The findings, thus, revealed a great diversity in how CNSs worked and as Farrell et al's (2011, p.160) study revealed a *'lack of clarity in titles, training, competencies and responsibilities is creating confusion'*.

Many interviewed healthcare professionals stated the CDU nurses' primary role was to ensure patients received their chemotherapy safely. Some healthcare professionals, but especially doctors, were adamant that nurses working in the CDU did not have time to provide psychosocial support to carers or indeed patients. McIlfatrick et al's (2006b) small phenomenological study aimed to explore the nurses' experience of working in a CDU. Their findings echo those of this study. The CDU nursing staff described significant work-related stress, created by the relentless pressure of the workload, limited space, inadequate teamwork and lack of available resources.

Allan (2001) conducted an ethnographic study, using participatory observation and interview methods, to explore the work of nurses at a British fertility outpatient clinic. While the setting was different, similar nursing practices were discovered. Both Allan (2001) and McIlfatrick (2006b) found nurses were '*nursing the clinic and the doctor*' rather than '*nursing the patient*'. While CNSs in this study described their main function was '*smoothing the way for patients*', many of them were observed to be 'nursing the MDT'.

The nurse participants suggested doctors' main focus was the disease. Doctors were perceived not to value meeting the supportive care needs of patients and carers. Indeed in MDT meetings supportive care needs were rarely addressed. Doctors, both formally and informally, acknowledged that the focus of this research was not a priority area for them. They too had significant pressures, increased workloads and large clinics. While the interviewed doctors recognised the important roles of the CNS and CDU nurses, most of the nurses described feeling unsupported and disempowered by the medical staff and organisation. Yet, there were contradictions. Some of the consultants were extremely protective and supportive of the nurses.

Meyer's (1993b; 1995) doctoral study aimed to explore the introduction of lay participation within an inpatient ward using action research methodology. It was at that time a very novel concept. Meyer's (1995) findings resonate deeply with those of this study. She worked with a MDT over one year and found numerous barriers which prevented the implementation of user and carer involvement. While quantitative findings indicated positive attitudes, the qualitative data revealed in reality most members of the MDT held negative views. Nurses were the key supporters. However, Meyer, (1993b) found nurses were prevented from changing their practice because of the attitudes and actions of others (mostly medics) in the team. Meyer (1993b, p. 65) concluded that if the policy goal for user and carer involvement was to be achieved, it was important '*that policy makers establish ways in which professionals can learn to work more closely together with a common strength of purpose and through understanding and appreciation of each other's roles and responsibilities'*. While improvements were found, it was woefully apparent that over two decades later very little had changed in practice.

8.6.5 Guidelines and Policy

There are gaps between the rhetoric of Government carer policies and professional guidelines and what could help healthcare professionals to address carers' needs within the current realities and constraints of the healthcare service. While policies (outlined in section 1.7) emphasise the need for services to support carers, they do not offer guidance nor identify resources to help healthcare organisations implement policy recommendations nor do they outline the parameters of carer involvement. While it is acknowledged that there are inherent difficulties with developing functional and practical clinical guidelines (especially when there is insufficient evidence) and also prompting practitioners to implement them, they should endeavour to bridge the gap between policies and practice (Grol et al, 2013; Cabana, 1999).

The NICE (2004) guidelines for improving supportive care for adults with cancer was, as identified in section 1.4, a highly influential document at the beginning of this study. Other countries including Australia, Canada, and the USA and multi-national organisations have over the last decade developed similar guidelines, (NHMRC, 2003; Hewitt et al, 2005; Adler and Page, 2008; Surbone et al, 2009; Turnbull MacDonald et al 2012). All these documents outline the need for healthcare professionals to support carers. However, the guidelines do not acknowledge the potential difficulties healthcare professionals can have when involving carers nor do they offer practical solutions (Turner et al, 2005). Rarely do they differentiate between the needs of patients and carers. The findings of this study, and others, have indicated these are frequently different and in conflict (Wilding, 2003; Stalker, 2003).

It is, therefore, not surprising that many of the aspirations presented in policy and guidelines are not well translated into clinical oncology practice. Indeed, most operational documents and protocols appear to either include the need to support carers as a tokenistic gesture, or not at all. An example, from many, is the patient Holistic Needs Assessment (HNA). This tool, introduced by the National Cancer Action Team (NCAT, 2007; 2011) was to be implemented at specific points during disease trajectory. While the HNA prompts practitioners to ask the patient about many different psychosocial concerns, for example, finances and the emotional impact of their illness, it does not ask the question, who supports you at home?

As previously mentioned in section 7.8.2, family and friends provide a significant amount of care to people with mental health problems. Although, clearly the manifestations and experiences of the illnesses are very different, carers in this setting share similar challenges and needs for support to those identified in this study. The Triangle of Care guidance (Worthington et al, 2010; 2013) was developed by carers to help healthcare professionals engage more effectively with carers. This guidance was not developed through research nor has it, so far, undergone evaluation of effectiveness, through rigorous research designs across multiple sites and settings. Yet, the guidance has been readily adopted by practitioners and implemented in numerous mental healthcare settings. Unlike the previously mentioned guidelines, the Triangle of Care outlines sensible how to do it advice and best practice case studies (Worthington et al, 2013). Many of the recommendations for practice, including staff training and tools used to engage with carers, could be readily adapted to other healthcare settings.

8.6.6 The Ethical and Professional Constraints

In this study and the literature, professional obligations of protecting patients' privacy and autonomy was frequently cited as being the main obstacle to sharing information with carers (Northouse et al, 2012; Reed, 2011). In contrast, many practitioners were observed to frequently disclose personal and sensitive information to both patients and their companions without verifying who the patient's companion was or whether the patient wanted them privy to the information. There are tensions between maintaining patient confidentiality and the requirement to provide carers with relevant disease and treatment-related information and support. Some practitioners, usually more experienced, acknowledged that they used different strategies to work around ethical constraints. However, patient confidentiality is a thorny issue, sometimes used as smokescreen by practitioners and one that will inevitably arise in any meeting held with carers (Worthington et al, 2013; Gray et al, 2008). Similar to the findings of Gray et al (2008) practitioners found current legislation for sharing information with carers negligible and confusing.

Only two documents were found, which clearly outlined the current professional and legal expectations. These were Confidentiality, Guidance for Doctors (General Medical Council, 2009) and the above mentioned Triangle of Care (Worthington et al, 2013). Both state that the patient must provide informed consent before any personal information is shared with carers. However, in the event that informed consent is not given by patients, healthcare professionals should always explore with the patient why this is the case. Even without their consent, carers should be able to access generic information regarding the patients' care (GMC, 2009; Worthington et al, 2013).

Very little empirical research seems to have examined what patients' perceive to be appropriate in terms of information sharing between carers and healthcare professionals. Gold et al (2009) used a survey design to explore the expectations of patients, their carers and physicians regarding the communication of clinical information to carers. The sample comprised 102 participants (51 patient and carer pairs), recruited from out-patient departments, the response rate was 8 per cent. Overall 567 surveys were sent to doctors from various specialities, 219 were returned, a response rate of 38 per cent. The majority of doctors (83 per cent) perceived discussions with carers should begin following the patient's permission and at the patient's request. However, the majority of carers (84 per cent) and patients (88 per cent) believed that carers should have full access to information. Furthermore, patients (52 per cent) and carers (50 per cent) perceived that information should be routinely offered to carers. Although, the small sample sizes and geographical location (Australia) limit the generalisability of this study, the findings indicated that patients and carers have very different expectations of information sharing to those of medical staff. Conversely, Benson and Britten (1996) conducted a small qualitative study and explored through in-depth interviews patients (n=30) views about GPs disclosing information to their families. The findings revealed that patients did not object to their relatives having pertinent information about their illness, as long as they had first provided consent. This is an area that clearly requires further exploration.

The NMC (2008) and the RCN offer little guidance to assist nurses in this aspect of supportive care (Rapaport et al, 2006; Gray et al, 2008). The NMC (2008, p. 1) code of professional conduct states, nurses *'must work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community.'* However, what it does not acknowledge is the tensions between the need for carers to have information and the practitioners' duty to protect patient privacy and wishes (Gray et al, 2008). There is an urgent need for a professional debate (particularly in nursing) to critically examine and clarify these issues.

While conducting this research the Francis Inquiry Report (2013) was published, this examined causes of the appalling failings in care at Mid Staffordshire NHS Foundation Trust during 2005-2009. The events that occurred had devastating effects on both patients and their families. While there had been previous investigations conducted by the Healthcare Commission their findings had proved unsatisfactory and subsequently acknowledged to be defensive (Francis, 2013). Consequently, CURE, a group established by Julie Bailey, the daughter of an elderly patient who had died in Stafford Hospital, initiated a national campaign, which demanded a more thorough investigation. This resulted in an independent inquiry led by Robert Francis QC. Hayter (2013, p.e1) contends '*one of the most concerning elements of the Francis Report was the inability of the hospital managers to listen to concerns from patients, families and some staff.*' Relatives made many complaints on behalf of patients, which went unheeded. What is striking about the report's conclusions is while it is acknowledged that both patients and their relatives/carers should be viewed as partners in the patients care, in the 206 recommendations relatives and carers were rarely acknowledged. While the inquiry examined the management of complaints, it seems the questions that no one has yet asked are what made it difficult for nurses and doctors working in the Mid Staffordshire NHS Foundation Trust to respond to the initial concerns and complaints raised by patients' families and carers or indeed what might make it difficult for practitioners to involve carers?

8.6.7 The Preparatory Meetings and On-Treatment Assessments

Another impact of the changes to treatment delivery is how patients are now prepared for treatment. The findings demonstrated that pre-chemotherapy consultations are one of the most crucial meetings patients and their carers will have in the acute cancer phase. Invariably, they are the first opportunity nurses have to begin fostering important alliances, orientating patients and carers to the service and sign-posting to other available resources (Epstein and Street, 2007). In effect this meeting sets the scene for the coming months of treatment. Yet, nurses called this essential intervention a '*chemo chat*'. Supposedly to help contain patients' anxieties, but by doing so, nurses downgraded the importance of these meetings and their expertise. During the forty-five minute consultation, most practitioners were found to focus entirely on providing information about treatment issues. Patients' and carers' psychosocial needs were not systematically assessed. Non-verbal and verbal cues, offered by either patients or carers indicating concerns and distress, frequently went unnoticed. As previously highlighted, carers were rarely actively involved. While practitioners recognised the potential benefits, they had concerns about including carers. They felt it added more complexity to this multifaceted meeting.

Consultations are most effective when an individualised, person-centred and organised, structured approach is used (Epstein and Street, 2007). There are frameworks which practitioners could use to provide a structure to conduct these meetings more efficiently and effectively (Fortin et al, 2012; Silverman et al, 2005; Redsell, 2006). However, a central component to the success of these meetings is emotional engagement (Cohen-Fineberg, 2011). Patients will rarely share their concerns unless the health professional encourages them to do so (Maguire et al, 1996; Farrell et al, 2005; Silverman et al, 2005; Cohen-Fineberg et al 2011). Yet, in this study practitioners seldom structured the meetings and avoided acknowledging issues of an emotional nature. It was a missed opportunity. Eliciting concerns can help practitioners to guide the consultation, ensuring that the information needed for patients and carers to be safe at home is relevant and understood (Silverman et al, 2005). Avoidance of concerns can also have a detrimental effect on patients' and carers' ability to absorb important but also frightening, complex and alien information (Maguire et al, 1996; Epstein and Street, 2007). It is, therefore, unsurprising that patients and carers reported that they continued to feel extremely uncertain about what to expect and how to manage after these consultations.

During consultations practitioners also needed to provide large amounts of complex information in a manner that was easily understood, with empathy and compassion as information about side-effects can also evoke distress. Information should be tailored to what the patient wants to know and can understand (Pitceathly and Maguire, 2003; Epstein and Street, 2007). This was found to be problematic for practitioners especially if the patient did not want to know very much, or had limited health literacy, which is often the case (Pollock et al, 2008; Epstein and Street, 2007; Manning and Dickens, 2006). Yet, it was vital patients and carers knew what to do if side-effects occurred at home. The findings revealed that conflict resulted from the carer wanting more information than the patient. Practitioners need to have the ability to use different communication and negotiation skills to ensure that both parties understand and are satisfied with the information received (Gilbert et al, 2010). It was found that this consultation was considered an isolated, self-contained event. However, patients' and carers' information needs should be continuously assessed throughout treatment, as their needs will inevitably change (Epstein and Street, 2007).

Patients, who received chemotherapy in inpatient settings, usually had three weeks to recover before their next treatment. Consequently, healthcare professionals did not see the effects of treatment on a daily basis and, therefore, were often unaware of the impact of treatment on both the patient and carer. While most patients did appear to be managing well when they attended for treatment, the findings revealed a very different picture. In interviews patients and carers reported struggling with problems at home, which the healthcare professionals generally knew nothing about. Similar to other reports, emotional concerns, nausea and fatigue were commonly under-reported (Mckenzie et al, 2007; Molassiotis et al, 2008; Ockerby et al, 2012). On-treatment assessments were conducted using chemotherapy toxicity checklists. These were described by many of the participants, patients, carers and healthcare professionals, as '*tick-box exercises'*. Nurses believed these tools prevented genuine engagement with patients. However, it was clear during the observations and interviews that the assessment tools were not the problem. It was how they were used.

8.6.8 Enabling a Person-Centred Approach in Pre-Chemotherapy Consultations: Educational and Facilitative Strategies

At the time this research was undertaken there was not a collectively agreed local approach, which determined the purpose, content and function of pre-chemotherapy preparatory consultations. Practitioners throughout this study recognised a need to address this aspect of care. The expert consensus meeting described in the previous chapter (section 7.8.1) began the process of identifying a shared professional understanding of the purpose of this important meeting. However, there is still much more to be done to enable CDU nurses to do this meeting and on-going assessments well.

As identified above, meeting the needs of both patients and carers in the same consultation requires practitioners to have sophisticated communication and interpersonal capabilities (Cohen-Fineberg et al 2011). While senior practitioners had recently undertaken advanced communications training (NCAT, 2013), CDU nurses were found to have had little educational preparation for this aspect of their work. Practitioners themselves identified the need for more training. Certainly, the need to develop educational initiatives to enable practitioners to put the concept of person-centred care into practice and improve communication skills is a frequent recommendation in most of the emerging literature (The King's Fund, 2013; NPSA, 2013; The Health Foundation, 2014).

A short three hour workshop called SAGE & THYME (recently introduced into the NHS) was identified as being potentially useful (indeed I attended the training myself). Connolly et al (2009) who developed the SAGE & THYME model state it is '*built upon the principle of partnership in care. The focus is on listening, clarifying and reflecting rather than imposing solutions to patients' problems. It guides health and social care staff to explore emotions and to respond appropriately while maintaining a supportive and safe structure for patients and staff alike'*. The first part 'SAGE' provides a guide for healthcare professionals to remind them to first listen and hear peoples' concerns before responding (it guides the health professional in). The second part 'THYME' provides guidance for responding to the concerns of others and management of potential distress (in other words it guides the health professional out again). Connolly et al (2009) state that while more research does need to be conducted, the initial evidence suggests that there are immediate benefits for those who have attended the course. These include '*increasing self-perceptions of confidence, competence and willingness to explore the emotional concerns of patients'* (Connolly et al, 2009). At the end of this study plans had been made to ensure that all the staff working in the CDUs would attend this training.

However, as a facilitator of Connected an advanced communication skills training programme (NCAT, 2013) I am aware of the challenges practitioners may experience when trying to transfer learning and new skills into practice. Indeed, Heaven et al (2006) argue that without organisational support, such as on-going clinical supervision, the effectiveness of communication and consultation skills training is questionable. This is why as identified in section 7.8.1 some nurse participants and I sought funding to support a small project. The funding was to be used to develop pre-chemotherapy consultation guidelines and a training tool, (a professionally developed film). It was envisaged that this tool could be used as a component of on-going facilitated, in house training. In groups nurses and other AHPs could watch the film, try out different strategies and share their challenges. Although we were unsuccessful in obtaining the grants, the idea was adapted and instead of presenting a film, role-play is being used to demonstrate and explore the communication skills as part of the local network's chemotherapy training updates.

Throughout this study I used strategies to enable 'safe spaces' for practitioners. The aim of this was to create some 'head-room' for practitioners, time to share their experiences and seek solutions to their problems (either on a one-on-one basis or in groups). In doing so the findings from the evaluation meetings (section 7.7) indicated that by simply enabling this facilitated space, person-centred communication and team-work appeared to improve. An initiative with similar ideals, 'The Schwartz Rounds', developed by a patient Ken Schwartz in the USA, has very recently been introduced into the NHS by the Point of Health Foundation (The Health Foundation, 2014). These facilitated monthly one hour forums or 'rounds' bring together multi-disciplinary healthcare staff to reflect (not problem solve) upon the human and emotional aspects of their work over lunch. Initial research evidence suggests that the 'Schwartz Rounds' are a beneficial source of support for staff, which may help to effect cultural change (Goodrich, 2012).

8.6.9 The Emotional Work

A central recurring theme throughout this thesis is emotions. Without doubt, healthcare professionals were confronted on a daily basis with difficult emotional work. Certainly a key obstacle to supporting carers was the potential for practitioners having to manage more. The slide presented at the workshop entitled '*being safe – feeling safe'* (Figure 11, section, 7.4.1), illustrated what had been interpreted as the important and equal value of both dimensions of the supportive care required by patients and carers during treatment. Healthcare professionals unquestionably needed to ensure that patients had their treatments safely. Indeed, after the initial treatments, patients and their carers did report feeling safe while patients were in the treatment suite. CDU nurses who participated in this study had sound technical competence and knowledge. They were also very responsible and caring. As Smith et al (2009) point out a caring nurse is one who ensures patients are safe when in their care. Yet, patients and carers also needed to feel safe when they were at home.

Hochschild's (1983) study has relevance here. She explored the work of service providers, in particular flight attendants, to describe the unrecognised and unrewarded work they did to induce feelings of being cared for and safety in passengers. Hochschild (1979; 1983, p.4) describes how this emotional work is guided by '*feeling rules'* the socially constructed ways that regulate how people should act in different home or professional situations. She suggests that there are two different types of acting involved in emotional management, surface and deep. Smith (1992) subsequently used the concept of emotional labour to investigate the hidden emotional aspects of nursing care work, including exploring how student nurses learn to care and how caring can impact on nurses. Smith (2012, p.12) describes surface acting as changing our outer expressions '*to make our inner feelings correspond to how we appear'*, while deep acting '*requires us to change our feelings from the inside using a variety of methods such as imaging, verbal and physical prompting so that the feelings we want to feel show on our face'*. Similar to Smith's (1992) findings, nurses acknowledged that they often acted in their roles, for example, they joked with patients to create a happy environment, which patients and their visitors valued highly. However, as Smith (1992) found, nurses revealed that emotional labour came at a cost, and was not valued by the organisation and some members of the MDT. The findings demonstrated that the gender stereotypical portrayal of caring that it is '*women's natural work'* and the '*power relations between doctors and nurses'*, which Smith (1992, p. 135) found, still exist. Nurses acknowledged in this study that the organisation, including most doctors did not value this aspect of care. Indeed, some doctors viewed this research as 'nice' but not vital. Doctors were more likely to engage with this study when they had a personal experience of caregiving and/or they were female, while some only participated when they were invited to attend the expert consensus meeting (section 7.8.1).

Inducing feelings of safety in carers required clinicians to acknowledge and manage the uncertainty created by the disease and treatment (Smith et al, 2009). Yet, while many of the healthcare professionals were extremely knowledgeable and had advanced technical skills, few appeared to be able or indeed want to engage with potentially distressing situations. Healthcare professionals revealed a reticence to engage emotionally with both carers and patients. They described emotions as '*worms',* which needed to be contained in cans or worse Pandora's Box (for this suggests if the box is opened all sorts of evils will be unleashed). Practitioners feared being overwhelmed by complex and potentially distressing situations, which they felt ill-prepared to manage or had little time or too few supportive resources to draw upon. Even asking what appeared to be a simple question, such as who supports you at home, had the potential for creating a difficult conversation. Therefore, the thought of addressing very complex family dynamics provoked much anxiety. As one carer suggested, they feared '*getting it wrong'*.

Feeling uncertain was an emotion, which was repeatedly expressed by practitioners and carers. Taylor (2005, p. 168) suggests '*when people confess to not knowing what to do in a particular situation it is not that they lack the kind of information they need, despite what they might say. Usually they have more information than they could ever hope to need'.* When people say they are uncertain what they really mean is that they do not have a '*frame of reference'* to draw upon to evaluate the information (Taylor, 2005, p. 168). Mezirow (1997, p. 5) offers an alternative view, people do have '*frames of reference'*, yet they are often inadequate as they consist of '*habits of mind'* and '*points of view'*, which they use to make sense of the world. Holbeche (2006) suggests it is these that need to be reframed. However, being uncertain creates anxiety. An emotion Illes and Vaughan Smith (2009) suggest people will actively try to avoid.

These findings echo those of Menzies' (1960) seminal work, who found socially constructed defences protected practitioners against the anxiety of having to address emotive issues. Nurses, for example, were able to hide behind routine tasks. Yet, conversely these actions added to healthcare professionals' personal frustrations and dissatisfaction with their work. However, the problem with these usually unconscious socially constructed defence mechanisms, while needed at one level to help practitioners and the organisation, is that they become emotional toxins if left unchecked (Edmonstone, 2013; Frost, 2003). These toxins not only impact on the well-being of the individual, leading to burnout, but also the organisation, for example, with low morale and high staff turnover (Bain 1998).

8.6.10 Managing Emotional Work

It would be unfair to suggest that all practitioners in this study avoided engaging with patients' and carers' emotions. Some nurses and doctors were observed to be extremely adept and capable of managing the emotional work. Salovey and Mayer's (1990, p. 189) theory of emotional intelligence (EI) perhaps explains why some people could do this, while others appeared to struggle. They initially defined EI as a '*subset of social intelligence that involves the abilities to monitor one's own and others' feelings and emotions, to discriminate among them and to use this information to guide one's thinking and actions'*. They have since refined this definition, while others have developed expanded EI models (Grewal and Salovey, 2005; Bar-On 2000; Goleman, 1998). Others have used different terms, such as emotional literacy (Freshwater, 2004) and emotional capability (Huy, 1999) to describe the skills of managing emotions. However, as Hurley (2012) identifies most EI models now contain a number of core capabilities, which include self-awareness, self-management, social awareness and relationship management.

However, EI is a concept which continues to attract much contentious debate (Specter, 2005). The main criticisms of EI are it is not intelligence rather personality traits and it is difficult, some argue impossible, to objectively measure (Ogle and Bushnell, 2014; Hurley, 2012; Locke, 2005). Yet, in the field of change management theory EI is now considered to be an essential component of professional and leadership effectiveness (King 2011). What is interesting about many of the discussions I had with healthcare professionals is how difficult it was for them to acknowledge and talk about emotion. They became embarrassed or upset and used euphemisms to describe the difficult emotional context of their work. Unsurprising, perhaps, as historically emotions in healthcare have been ignored or sanitised (Cherry et al, 2012). Indeed, it was thought to be advantageous for healthcare professionals to maintain an objective, emotionally detached stance (Maben et al, 2006; McQueen, 2004). However, this view over the last twenty years has been increasingly challenged and the need to develop emotionally capable healthcare professionals has gained even more momentum since the recent events at the Mid Staffordshire NHS Foundation Trust (Cherry et al, 2012). As this research has demonstrated, practitioners do need to ask the question, how are you? And be able and prepared to hear the answer (Orbach, 1999; Freshwater, 2004).

Educational programmes for healthcare professionals do not adequately prepare people to become emotionally capable (Heron, 2001; Freshwater and Stickley, 2004; McQueen, 2004; Hurley and Linsley, 2012). Rather than equip practitioners to manage the inherently complex and uncertain nature of their work, education (especially in chemotherapy nursing) remains focused on knowledge and technical skills, which are measured by objectively assessable competencies (NHS England, 2011). As Illes and Vaughan-Smith (2009, p.18) suggest education in healthcare '*tends to focus on what people do, not on the kind of people they become'*. Most of the nurses in this study were well educated. They understood in theory what carers needed. However, what was lacking was help to manage the relational and emotional aspects and to integrate their knowledge and learning into practice.

Smith's (1992) findings revealed that nurses acquired emotional management skills by working with role models and from being supported by capable ward sisters. However, in the research settings it was found that there are currently few opportunities for inexperienced nurses to watch more expert nurses perform difficult communication tasks. Much of the nursing work was done on an individual basis, behind closed doors. Nurses working on the CDU did not have nursing handovers or formal strategies for sharing information with others in the team. They had little time to think, with few formal opportunities to do so together. However, there was a conundrum. Similar to Allan's (2001) findings, while most nurses went to great lengths to explain that working with patients and their families in this environment was really difficult, for which excellent communication skills were vital; few had independently sought help or formal support mechanisms, such as clinical supervision, to improve this aspect of their work. To do so, would mean confronting the anxiety created by their work (Menzies Lyth, 1988). Yet, as Illes and Vaughan Smith (2009, p.15) suggest *'healthy responses to this professional anxiety involve bringing it into awareness, reflecting on the source of it, seeking support where we need it, thinking carefully through the needs and wishes of the other, reminding ourselves of our sense of purpose'*.

8.6.11 Wicked Problems

This research has demonstrated that the policy and service priorities for providing better support for carers have become a 'wicked problem'. Wicked problems are defined by Grint (2008) as complex problems, for which there are few certainties and are, therefore, not easily addressed or solved. They are not 'critical problems', which require a rapid response to a crisis nor 'tame' problems, those that have been experienced before, more easily resolved because there are tried and tested solutions (Grint, 2008; Edmonstone, 2013). It has become a wicked problem because there remains, within policy, organisations, healthcare professionals and society, uncertainty, confusion and mixed messages about the involvement of carers in the patients care. Indeed, the disconnected model of involvement (Figure 17) exists at every level of the healthcare system, including policy.

Plesk and Greenhalgh (2001, p. 627) suggest when practitioners are confronted with wicked problems their '*learnt instinct, with such issues, based on reductionist thinking, is to troubleshoot and fix things – in essence to break down the ambiguity, resolve any paradox, achieve more certainty and move into the simple zone'*. Yet, wicked problems, such as those reported in this study, do not have simple zones (Grint, 2008). Consequently, in healthcare organisations a state of inertia develops, defences are erected and the problems become entrenched (Bain, 1998). Carers and their needs remain ignored until a crisis occurs and then they become a critical problem. Uncertainty and paradox will always be an inherent component of healthcare

(Schapira, 2014; Fraser and Greenhalgh, 2001). Therefore, as highlighted at the beginning of this chapter the challenge is to enable practitioners who work in complex environments become capable (rather than just competent), to address complex problems and manage the uncertainty as effectively as the current constraints of practice will allow (Kernick, 2011; Hurley, 2012; Fraser and Greenhalgh, 2001). However, wicked problems cannot be addressed by one group alone. They require transformational organisational change, with interventions that target underlying workforce and organisational factors (Holbeche, 2006).

8.7 Transformational Organisational Change: Mental Healthcare and Carers an Exemplar

Throughout this study I endeavoured to engage with other researchers and healthcare professionals who also had an interest in developing strategies to support carers. As identified in section 8.6.6 I met with staff who worked in regional mental healthcare centre. Through this engagement I became aware that the Triangle of Care guidance (Worthington et al, 2013) had been successfully adopted by clinical staff throughout the Trust and beyond. This had been achieved because a transformational organisational development approach, steered by senior nurse leaders, who had involved all members of staff and service users, had been followed to implement this document’s recommendations for involving carers. These included training for staff to raise awareness and enhance communication skills (ideally in collaboration with carers); carers are identified as soon as possible in the acute episode; policy and informative practice protocols should be available; there are defined posts in place to lead and champion carer issues; an introduction to the service specifically for carers is available, such as information sheets; and finally carers are signposted and able to access support services and voluntary organisations, for example, Rethink (Worthington et al, 2013). The findings of this study indicate that cancer services would need to adopt a similar transformative approach to enable ‘carer awareness’ to become a normal part of practice and culture.

8.8 The Modelling Phase: Exploring Solutions, Enabling Change

In the methodology chapter (section 3.7) a number of important theories for managing behaviour and organisational change were described. Indeed it was argued in Chapter 3 that the first task when developing interventions is to understand whose or what behaviours the intervention needs to target (MRC, 2008; Michie et al, 2008). At the end of the pre-clinical phase the findings indicated that the intervention which helped carers the most was skilled healthcare professionals who had carer awareness and emotional management capabilities. While all practitioners had a supportive care role it was predominately a nursing domain. Yet, it was health professional and organisational behaviours, which generally prevented carers from being prepared and supported by nurses in the chemotherapy setting.

The modelling phase, using action research methodology, provided an opportunity for nurses to explore the feasibility of some of the identified strategies healthcare professionals could use to support carers (Table 23). This next section will draw upon some of the behaviour change and organisational learning theories to examine how in this study participants were enabled and began to change their behaviours towards carers.

8.8.1 Becoming Aware and Owning the Problems

An extremely significant finding, which greatly impacted on the participants, was described in a slide as '*the tale of two chairs'*. Argyris and Schon's (1974) theory of the need for double loop organisational learning is particularly relevant here. This theory proposes that people are rarely aware, without being challenged, that their beliefs are incongruent with their actions. Healthcare professionals were unaware of the way carers were oppressed or prevented from being involved in the patient's care by practitioner and organisation behaviours. The picture of the visitors' and nurses' chairs, seen in section 7.4.1, demonstrated how even the most caring health professional can overlook the obvious. It illustrated that there were indeed unconscious defences in place (Bain, 1998). It was an extremely simple but powerful image, which captured the nurses' attention, challenged their beliefs and motivated them to take action. In essence this picture and other findings presented in the workshops acted as triggers. These were needed as proposed by Lewin's (1947) three stage transitional model of change, to unfreeze the participants and create awareness that change may be required. Having become aware that change was required, participants began to claim ownership of the problems. An imperative if change is to occur (Hayes, 2010; Bain, 1998).

8.8.2 Transformative Learning Theory: Creating Safe Spaces

Creating safe spaces for people, either individually or in groups, to share their ideas and critically reflect was the most important factor for enabling participants to start changing their behaviours. Bain (1999, p.425) suggests '*organisations that lack learning space or reflective space which allow for organisational awareness are asleep to their own behaviour'*. As identified previously, practitioners had few formal opportunities to come together as group. Yet, when they did, they became aware of the socially constructed defences which were preventing practitioners engage with and support carers. The unconscious became conscious. Mezirow (1997) would describe this process as transformational learning. He explains through critically reflecting on their assumptions, people can reframe their '*habits of mind'* and '*points of view',* also described as values, feelings and beliefs, which in turn enables people to transform or change. However, Mezirow (1997, p. 6) contends this transformational learning cannot be done alone. It requires '*communicative learning'*.

Conducting this research at two sites provided some enlightening insights (section 7.7). The practitioners at Site 1, although apprehensive, started using the developed tools as soon as they were delivered to the site. They acknowledged that they used these tools as '*props*', which enabled them to engage with carers without undermining or upsetting the patients. Initially, the nurses at Site 2 did not use these tools. There were many reasons including a lack of planned involvement, inadequate leadership, lack of ownership, an uncertainty of the tools' worth and also anxieties about using them. However, by creating a safe space to listen to the nurses' views and concerns prompted a shift in attitudes. The conversations continued after the meetings and participants shared different approaches to the pre-chemotherapy consultations. They started to use the tools. Subsequently, the nurses (and some doctors) on both sites reported the tools had been well received by most patients and carers. This then gave them further confidence to keep experimenting with the tools and more importantly engage with carers.

What happened in the participatory meetings is described as praxis, a vital feature of action research (Hockley et al, 2013). This is defined by Rolfe (1993, p.176) as the '*bringing together of theory and practice, involving a continual process of hypothesising and testing out new ideas and modifying practice according to the results'*. In these meetings practitioners were asked to reflect upon their experiences of offering the support notebooks and fridge magnets to carers. The assumed and unanticipated consequences of trying out new and different ways for engaging with carers were challenged and addressed. The participants shared with each other different strategies they could use to engage with carers and manage unforeseen difficulties. This provided new sources of emerging data and further insights about the problems. In the meetings participants were challenged by the facilitators and also each other when inconsistencies or contradictions occurred within their version of events, especially if these appeared to be at odds with their previously observed and acknowledged behaviours.

An important factor, which enabled nurses to begin changing their behaviours, was the key participants (who the nurses considered to be expert nurses). They acknowledged that they too had been anxious initially about trying out the tools and initiating the conversations with patients and carers. As one key participant remarked '*it was tricky'*. Changing behaviours required the practitioners to be brave. They needed support from role-models and each other. As Maben et al (2010, p. 10) propose '*really relating to patients* [and carers] *takes courage, humility and compassion, it requires constant renewal by practitioners and recognition, re-enforcement and support from colleagues and managers. It cannot be taken for granted'*.

8.8.3 Leadership

The key participants were essential for enabling change. They were people Rogers (2003) would describe as 'innovators'. They supported the study from the onset, identified and took forward new ideas. However, what they also provided was clinical leadership through skilled '*know-how'* (Manley et al, 2005, p. 24). They enabled others by being willing to share their experiences and were able to adapt and think through alternative approaches, while at the same time using what available resources there were. Finally, they could '*envisage a path through a problem/situation and invite others on that journey'* (Manley et al, 2005 p. 24). Grint (2008) suggests wicked problems, where there is so much uncertainty, require leaders who are willing '*to ask the right questions rather than provide the right answers because the answers may not be self-evident and will require a collaborative process to make any kind of progress'*. The key participants were willing to demonstrate to the others that it was acceptable not to have all the answers and solutions because the problems were complex. They were at ease with uncertainty (Grint, 2008). In doing so they displayed great capability for managing change (Fraser and Greenhalgh, 2001, p. 799) and transformational leadership (McCormack and McCance, 2010; Kernick 2011).

8.8.4 The Importance of Critical Facilitation

Action research requires researchers to adopt a facilitator role. A vital ingredient for change is the effectiveness and flexibility of the facilitator. Facilitation can simply mean a '*process of enabling'* (Ryecroft-Malone and Bucknell, 2010, p. 117) or in other words 'to *make things simpler for others'* (Kitson et al, 1998 p. 152). In all the participatory meetings the purpose of facilitation was to create space and time to enable participants to reflect upon and make sense of the findings and their experiences, and find ways to move forward and change (McCormack and McCance, 2010). Yet, there was more to the role than this. If practitioners were to transform their practice they needed to be challenged. This required as Mezirow (1997, p.10) suggests becoming a '*provocateur*'; someone who encourages people to critically reflect and '*redefine problems from a different perspective'*. While White (2006, p.22) might describe this role as a '*reflexive trickster'*, not someone who sets out to deceive rather someone who is a boundary crosser, exposing new distinctions and making the usual, strange.

However, with this role came great responsibility. Challenging practice and sharing unpalatable findings was difficult when people were trying to do their best in the circumstances they are working in. It created what Lofland et al (2006, p. 30) have described as an '*ethical hangover: a persistent sense of guilt or unease over what is viewed as a betrayal of the people under study.'* This was because having become very close to the participants I then had to share with them findings, which did not necessarily portray them in the best light. Ensuring there were co-facilitators at all the participatory meetings was essential; they acted as a buffer and encouraged the participants to question. To their credit the participants mostly viewed the findings as an opportunity to constructively develop their practice rather than a maligned account of their work, which of course was the intention.

8.8.5 An Unanticipated Role

Throughout this study practitioners were encouraged to tell their stories. Very often these were not about patients and carers. Instead they described their anxiety and despondency created by the organisational changes and their relentless workloads. Initially frustrating, it soon became evident that they needed to share their uncertainties and distress about their work before they could engage with the research. In effect I started to become an '*emotional toxins handler'* (Frost, 2003). During organisational change this role is usually undertaken by managers (Shanley, 2007). However, at the research sites senior managers were mostly absent from the units, indeed, they too were overwhelmed. Instead I was there willing and ready to listen. Shanley (2007) suggests toxic handlers provide emotional support by *'listening empathetically, suggesting solutions, working behind the scene to prevent pain, carrying out the confidences of others and reframing the messages'*. Frost (2003) contends that while toxic handlers are vital to the health of an organisation and are particularly important in times of change and intense stress, they can become susceptible to suffering themselves. Indeed at times I found hearing so much anxiety, distressing. Hubbard et al (2001) highlight that researchers inevitably undertake emotional labour and should seek support to help them manage. Some members of the advisory group became close critical companions, who Manley et al (2005, p. 12) describe as '*partners who act as a resource on a journey of discovery – someone who can be trusted, a supporter who has a genuine interest in development and growth providing high challenge and high support'*. They were invaluable and enabled me to continue listening to others.

8.9 Reflection on the Methodological Approach

This study started with an engaged scholarship and participatory intent, underpinned by the initial iterative phases of the UK MRC (2000; 2008) Framework for Development and Evaluation of Complex Interventions. This framework was used for pragmatic reasons. The MRC guidance (2008) recognises that developing complex interventions takes considerable time, it is not a linear process, and it must begin with an in-depth analysis of the problem and its causes. Importantly however, it provided a useful way to present the different phases in a format that would be easily recognised and understood by those who were reviewing the applications for funding and ethical approval.

Choosing to follow an engaged scholarship approach explicitly acknowledges that involving others in the research process is vital. By adopting this approach I was obliged to not only undertake ethically sound research but to make the findings accessible through facilitation and teaching (Van de Ven, 2007). However, authentic engagement was found to be extremely challenging, it required time, energy, tenacity, commitment and resources. A principle objective of the pre-clinical phase was to foster involvement and develop relationships. Though, this at times proved to be a problematic balancing act. I needed to maintain an objective stance (because of the methods I was using) while being honest and open with those I was observing. However, from the beginning of the study, I endeavoured to create facilitative milieus (safe spaces), ones which would enable people to openly contribute. This depended on being able to use sophisticated facilitative skills and having high emotional awareness (because people feel anxious and at times vulnerable especially when they are doing the best they can in difficult circumstances).

I would argue that action research is an appropriate and valuable methodology to use in the modelling phase of the MRC (2008) framework. An important aspect of the modelling phase is to understand what may be feasible in practice, through an iterative process of experimentation (Michie et al, 2008). However, it is acknowledged that adopting a different methodological approach may have afforded opportunities that action research did not. I could have perhaps developed guidelines and tools myself with input from the carer advisory group and then tested these in practice, following one of the knowledge transfer methods outlined in Chapter 3, for example, Grol's 4 step model (Grol et al, 2013), to implement the intervention in practice. While this may have afforded more control over the research and perhaps offered different insights it would have limited the research in other ways. Although healthcare professionals espoused the notion of supporting carers, using an action research approach uncovered practitioners' uncertainty about how to involve carers and the worth of doing so. I was, therefore, able to expose the dichotomy between nurses' values and actions and gain a deeper understanding of the problems faced by practitioners. Action research differs from most of the implementation methods by explicitly incorporating the use of reflection as part of the process. Through shared group reflection nurses were able to explore what may be feasible and have support to make changes to their practice, which other methods might not have done.

As identified in section 8.4, action research is challenging. The research felt at times uncontained and lacking rigour. This was because involving others, who undoubtedly worked in complex adaptive systems, meant that introducing or instigating any kind of change inevitably created an impact somewhere else (Plesk and Greenhalgh, 2001). I would describe it as the 'ripple effect'. Consequently some actions occurred, which I was unaware of or could keep abreast of. This then creates difficulties when trying to systematically evaluate the research and understand what enabled the changes. This was also frustrating because ideas and actions would be shared by others who did not acknowledge where they came from. In PhD research this can create tensions if you are trying to add a unique contribution to the body of knowledge and for researchers generally who must demonstrate impact. It was also frustrating for the nurse participants to see their work used without acknowledgement. In future I will pay greater attention at the beginning and during this type of work to ensure everyone who is involved agrees and understands how the findings should be shared and how the work should be acknowledged.

In chapter 3 I highlighted that there are misconceptions about action research, especially with where it fits with service/practice development initiatives. Indeed throughout this study I have been asked by funders, service providers, researchers and members of the ethics committee to explain the difference. I struggled to provide a meaningful answer. Brain et al (2011) attempt to clarify and make distinctions between the different terms used to describe service development and action research. They acknowledge that there are overlapping commonalities between the two; both have the goal of developing practice through the implementation of change and both should be conducted systematically and rigorously. However, they suggest that action research is different because it aims to generate new knowledge where there is limited or no available evidence and the findings have the potential to be generalizable or transferable. Whereas service development initiatives and implementation methods are focused on effecting change where there is strong evidence available and are generally context specific. I would argue that the differences are somewhat arbitrary. Clinical settings are continually changing and evolving. Therefore, new knowledge is constantly being produced. I would also argue that differentiating between research (all research) and practice development creates artificial barriers in practice and is perhaps one of the main reasons why the so called 'knowledge-implementation gap' exists.

Interestingly, McCormack et al (2013) provide a different perspective. They suggest that action research is used to answer specific research questions, through cycles of action and evaluation. Whereas, they define practice development as: 'a *continuous process of developing person-centred cultures. It is enabled by facilitator who authentically engages with individuals and teams to blend personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformations of individual and team practices. This is sustained by embedding both processes and outcomes in corporate strategy'* (Manley et al, 2008, p.9). However, these researchers acknowledge that the process is complex and should be underpinned by action research methodologies. Furthermore, they argue that practice development is not currently valued by researchers, research funders and policy makers and recommend, as I have done, to position this type of work as a complex intervention using the MRC (2008) guidance (Manley et al, 2013).

At the beginning of this study I believed myself to be a pragmatist (section, 1.13). While I would consider myself still to be this, it is more in-line with the philosopher John Dewy's notion of pragmatism '*we learn by doing and realising what came of what we did'* (Dewey, 1938, cited by Rolfe, 2011, p. 34). However, as the study evolved it became clear that critical theory and in particular the work of Habermas (1972) underpinned the methodological approaches I was adopting during this study. Critical theory is complex for the novice action researcher and difficult at times to follow or even to describe (Rolfe, 2011). However, researchers who adopt this philosophical stance fundamentally seek to reflexively and critically understand 'what is' and 'what are the possibilities'? (Hockley et al, 2013).

8.9.1 Developing my Skills and Knowledge

Undertaking this type of participatory research requires researchers to have a range of transferable skills in both research methods and managing change and people (Stringer, 2007; Williamson et al, 2012). At the beginning of the study I was aware that I needed to develop and refine my skills and knowledge in these areas, as well as learn about research processes and methods (Meyer, 2010). In light of these needs I attended numerous training events and courses, throughout the project (see Appendix 20 for a comprehensive list). I received five sessions from a qualified professional development coach. This person had considerable specialised expertise in supporting the professional development of those working at a strategic level within the NHS. These intensive sessions predominately focused on enhancing my emotional intelligence and political competence, further developing intrapersonal and interpersonal skills. I also attended an Action Research course at the University of Ulster in June 2013. Here I was able to hear about other researchers' challenges and reflect upon different creative styles used in participatory research. Although I had in previous roles developed a facilitative style for teaching and clinical supervision, to help me conduct this work I read extensively around the skills of facilitation. Heron's (2001) creative and practical guide for helping clients was found to be extremely useful. This guide highlights the different facilitative approaches that can be used, for example, when and how to use confrontation skills if people's actions are not congruent with their espoused beliefs. As previously highlighted, what aided critical reflexivity and challenged my own 'taken for granted assumptions' was having 'critical companions' support me throughout the research process (Titchen, 2003; Manley et al, 2013). They, as well as members from the carers' advisory group and my supervisors, frequently challenged and provided alternative viewpoints.

8.9.2 Assessing Success

Bradbury and Reason (2001) suggest the quality of participatory research should be judged by whether the findings provide new insights and knowledge, both practical and theoretical, and lead to change. However, it is highly unlikely that practitioners will be able to sustain the changes initiated within this project without further organisational and facilitative support. Indeed Bain (1998, p. 416) argues without organisational learning throughout what he describes as '*system domains',* in other words the systems within which the organisation sits, change will only be transient. Alternatively, Meyer (2006, p 278) suggests the success of an action research project should not be judged on whether the objectives have been met or great change has been achieved, as it is *'unrealistic to assume change will be sustained in an ever-changing healthcare system'*. Rather the quality should be judged instead on its success for the learning and knowledge obtained by those who either conducted or participated in the research (Meyer, 2006). As well as gaining new insights and understanding, undoubtedly the findings, reported in Chapter 7, demonstrated that the nurses who participated learnt much by being involved in this study. I would also argue that an important determinant of success is that the relationships, established within the research, endure and are sustained after the project has come to an end. As highlighted at the end of Chapter 7, work and the conversations continue.

8.10 Ethical Issues

There were a number of unpredictable and difficult moral dilemmas that needed to be addressed throughout this research. Participatory observation is not an easy method to conduct ethically (Moore and Savage, 2002). Ensuring that all those who participated did so with full knowledge and freely provided consent was difficult due to the transient nature of the settings. If people who were not known did enter the unit I would endeavour to introduce myself, explain my presence and seek verbal consent but this was not always possible. The data gained through observing people who may not have provided full consent, therefore, required careful consideration (Mulhall, 2003). The findings were written up very carefully. Verbatim quotes, for example, were only used from those who had provided full consent. The cancer units were small and everyone knew each other. It was for this reason that the participants, especially healthcare professionals, have not been described in great detail. While conducting this research on two sites was problematic and time consuming, it helped to maintain the anonymity of participants.

The requests made by the ethics committee to ensure that all participants were informed of the research greatly disrupted the work of the units. Similar to Moore and Savage's (2002) experiences, patients struggled to understand the need for such stringent formal consent procedures as they perceived being observed as inconsequential. The processes instigated by the REC created greater expectations and anxiety for patients. It was for this reason that a substantial amendment was submitted to the ethics committee to change how patients and their visitors were informed about the observations.

However, it was debateable how informed participants really were. Sometimes patients would talk to me as though I were their nurse rather than a researcher. When this happened I would answer, if able, their questions but would usually fetch a nurse. Some patients did confuse me for a student nurse while I was wearing a uniform, to the amusement of staff. They would tell me for example, '*that I would learn a lot'* from whoever I was observing. It was clear in these instances that while patients had received study information sheets they had not fully understood my research role. I developed a quick way of explaining the research, for example, why I was there and what I would be doing. I found I needed to do this very concisely with simple terminology for patients as well as for healthcare professionals.

The interviews were particularly morally challenging as they compelled both patients and carers to consider issues they had not thought of before. Indeed I was undeniably *'opening a can of worms'*, exposing many difficult and sensitive issues. Interviewees (including some healthcare professionals) became at times extremely emotional. Consequently, I would often leave interviews with a great sense of disquiet. Plant (1995) explored family members' experiences of newly diagnosed cancer patients. She also described feeling extremely uncomfortable when leaving participants. Similar to Plant's (1995) experiences, participants did share with me why they had decided to be interviewed. They felt the research was important and would help others. However, it became apparent that for most this was the first opportunity they had to talk in any depth about their experiences and feelings to someone they viewed as impartial and who was willing to listen, 'warts and all'. This included some of the healthcare professionals who struggled with the emotional side of their work and/or their experiences of being a family caregiver.

In the literature, interviews have been described as having a potentially cathartic and therapeutic role. Carers especially have been found to view participating in interviews as a useful coping mechanism (Funk and Stadjduhar 2010; McIlfatrick et al 2006c; Plant, 1995). However, this was not the case for the interviewed patients. Although supportive of the need for this research and aware of the purpose of the interview all three participants focused on their experiences, rather than the needs of those supporting them. When they did talk about their families, they became distressed. Talking in-depth about how their disease and its treatment had impacted on their families was too painful, especially as they were either still having treatment or had just finished. They were not sufficiently distanced from the treatment experience to be able to reflect on their own experiences, let alone on the experiences of those they cared about.

They were all debriefed after the interview and then contacted by phone a few days later. However, it was for this reason that I stopped recruiting patients for interview.

At the end of the pre-clinical phase I had assumed that I would need to apply for further ethical approvals to continue the study. However, the REC and R&D committees both deemed this phase as service development. As it focused on staff a further IRAS application was not required. Yet, healthcare professionals in this type of research are just as vulnerable (if not more so) than patients. There were ethical challenges, which arose throughout the modelling phase of this study. Informing participants of what actions might occur before the modelling phase began was impossible. Some nurses may have believed they had no other choice than to participate in the study. Therefore, there was a high risk of manipulation and coercion. Protecting anonymity was difficult when I had, for example, little control over the conversations that occurred outside the meetings. It is for these reasons that I asked the REC and R&D committees to extend the time-frame of the study and as recommended by Froggatt et al (2013) at each stage written informed consent was obtained.

Hallowell et al (2005) state rather than help researchers manage ethical challenges that arise in this type of social research, RECS can add to them. Adhering to good ethical conduct, therefore, becomes the responsibility of the researcher. They argue, to be ethical researchers need to '*understand the ethical guidelines, gain approval from the ethics committees and have the best of intentions, but first and foremost we have to be constantly aware of who we are, where we are and what we are doing'* (Hallowell et al, 2005, p. 152). An unanticipated benefit of engaging others in this work was that advisors, from both the carer and stakeholder groups, played an invaluable role in helping address and manage some of the ethical and moral dilemmas that arose during this study.

8.11 Dissemination Plan

Dissemination of findings through publication and conference is extremely important if researchers wish to make an impact and influence others in their field (Dunleavy, 2003). I have already disseminated the findings at different and diverse events (see appendix 21). In doing so I was able to network with others working in the field and create connections. The table below outlines initial plans for dissemination of findings through both peer-reviewed and nursing publications. However, one of the challenges of participatory research is acknowledging the work of participants, while maintaining anonymity. The practitioners involved in this study would like their work to be acknowledged. We have already reported to the regional network instigating further projects and a joint paper is planned to disseminate the findings of the pre-chemotherapy consultation work.

Table 25: Planned Papers

Title	Potential Journal/Audience
Action Research: A Useful Approach for The Modelling Phase of the MRC Framework for Complex Interventions?	Methodology focused peer-reviewed journals e.g. Journal of Research in Nursing or International Journal of Nursing Practice
‘It’s Complex’: The Importance of Enabling Nurses to Prepare and Support Carers in the Chemotherapy Treatment Setting	Peer-reviewed cancer journals e.g. Supportive Cancer Care or Psycho-Oncology
‘It’s not a Chat’: Conducting Pre-chemotherapy Consultations.	Joint submission to a relevant nursing professional journal e.g. Cancer Nursing Practice
Innovative Approaches for ‘Wicked Problems’: The Importance of Engaged Scholarship and Clinical Nursing Academia	Submit to a relevant research focused peer-reviewed nursing journal e.g. Journal of Advanced Nursing or Journal of Research in Nursing,

8.11.1 Plans for Further Research and Developing Practice

Continued planned engagement with the practitioners who have participated in this research will also support dissemination of the findings and implementation of knowledge into practice. Since this research study has ended I have been asked by CDU nursing staff at the regional cancer centre (who were supported by the leadership team) to continue with the work started in this study. The aim of which is to help these nurses embed a more person-centred culture within the unit. We hold regular meetings and in these we are currently developing a shared philosophy. All the staff will be attending communication skills training to help them to improve their skills for identifying concerns and managing potential distress (SAGE & THYME, Connolly et al, 2009). It is envisaged that this training will be built upon and supported in regular chemotherapy updates within the units. Other work is also planned. Practitioners, patients and carers all appeared to value the support notebook and fridge magnet. However, further research is required to understand the perspectives of patients and carers. Applications for a small research grant will be submitted to support this work. The nurses who developed the tools also want to continue with this work and explore the possibilities of adapting the support notebook into a piece of software or app for hand-held devices. All this work is being underpinned by McCormack et al’s (2013) practice development framework, which itself is underpinned by action research methodologies and critical theory.

Chapter 9 Conclusions

'*Never doubt that a small group of thoughtful, committed, people can change the world. Indeed, it is the only thing that ever has.'* (Margaret Mead, 1901-1978)

The study reported within this thesis has provided some important and elucidating insights. The rapidly evolving changes to services and the shift to treatment delivery from in-patient to outpatient settings have irrefutably created challenges for the service, healthcare professionals, patients and their carers, which were rarely encountered twenty years ago.

From the findings it seems simple. Involving carers from the beginning of treatment could enable them to become important allies for healthcare professionals. They are a useful and vital resource for financially impoverished organisations and time pressured healthcare professionals. Indeed it would be difficult to envisage how chemotherapy services could manage without the support carers provide to patients. However, the findings have shown healthcare professionals, while seeming to understand the important roles and challenges carers have, largely failed to acknowledge their value and give them the support and comprehensible information they need. Undeniably carers and their needs were often ignored.

The findings presented in this thesis offer a different perspective from most reports of research previously conducted in the field of cancer carers. Unique to this research is that the perspectives, experiences and needs of healthcare professionals have been carefully examined. In doing so this research has provided many explanations for why carers are frequently excluded in the patients' care by clinicians. Undeniably involving carers is complex. However, the challenging nature of this work is currently not recognised by policy-makers, nursing professional bodies or the research community.

These are crucial findings and ones which may have relevance to other clinical settings. Through sharing the findings with project advisors and at local events and conferences, it was found that the problems identified in this study resonated deeply with many other healthcare professionals who worked within different health settings. They too experienced many of the challenges and barriers, presented in section 6.2, which prevented carers receiving support from practitioners.

9.1 Implications for Practitioners, Practice, Policy and Research

While on a superficial level the aims of this research appear to be met, there remains much more work to be done before carers of chemotherapy patients are prepared for and supported in the important roles they have. The findings demonstrated there are numerous professional, organisational, patient, carer and individual practitioner attributes, which can cause significant obstacles for healthcare professionals in delivering on this aspect of supportive care and, therefore, prevent carers from receiving the vital information and support they need. Involving carers in patients' care is complex and challenging for healthcare professionals who are working within constantly changing clinical environments and have unrelenting workloads. The current political drivers are for saving money but not reducing the quality of care. What became extremely apparent during this study is there are far more expectations of staff with less resources available to them. The nurses reported frustrations and tensions between the need to deliver an efficient, safe service with providing supportive, person-centred care in extremely busy clinical environments. The findings revealed that interventions were required, which would enable nurses to lead on this aspect of supportive care and enhance the preparation and support received by both patients and carers. Person-centred care is not just about service providers being able to '*see the person in the patient'* (Goodrich and Cornwell, 2008) but also the people behind the patients (carers) and the people who work within the system and deliver services (staff) (McCormack and McCance, 2010).

During the later stages of this project the short title for this study was changed to, 'Time to Think about Carers', as it was apparent that it was time to do so. The findings demonstrated there are considerable implications for policy decision makers, professional bodies, healthcare organisations, and researchers. It is time for all to think about how they can enable and support healthcare professionals.

9.2 The Recommendations

The main recommendations from this study are in consonance with emergent thinking about how best to deliver person-centred care, which incorporates carers' needs, and enhance patient safety in the NHS (Dixon-Woods et al, 2013; The King's Fund, 2013; NPSA, 2013; The Health Foundation, 2014).

9.2.1 Recommendations: Nurses

The foremost contention of this thesis is that nurses must be enabled and have continuous on-going support for developing and enhancing their capabilities and skills for managing the very complex and busy settings in which they work and to meet the current aspirations for person-centred care, which incorporates carers. The findings of this study demonstrated that nurses theoretically understood carers' roles and the contributions they made to patients' care. Indeed they were able to articulate these better than the carers. Yet, nurses were found to have few resources to draw upon to help them manage the relational and emotional aspects of this work and to integrate their knowledge about carers into practice. In this study what enabled nurses was the creation of reflective learning environments (safe spaces), in conjunction with critical facilitation and leadership from role-models, which provided high support and challenge

(McCormack et al, 2013). It is strongly recommended that those leading healthcare organisations should value, encourage and enable similar learning opportunities, as well as on-going training in communication skills, such as SAGE & THYME and staff support initiatives, such as Schwartz Rounds (Goodrich, 2012). Practice development initiatives should be viewed as an on-going process rather than one-off events so that changes can become embedded within clinical practice (McCormack et al, 2013) However, nurses should accept that an important component of person-centred care is to identify and manage peoples' concerns and emotional distress. To do emotional work well, requires self-awareness and courage (Maben et al, 2010; McCormack et al, 2013) Therefore, nurses have a personal and professional responsibility to seek out and engage with supportive strategies to continue developing their skills and capabilities.

9.2.2 Recommendations: Carers

Service providers need to be able to acknowledge the important roles of carers and valuable contributions they make to ensure patients remain physically and emotionally safe while at home. Simple actions initiated by healthcare professionals can demonstrate 'carer awareness', such as asking for the names of those who attend with the patient, and including them in conversations and consultations by seeking out their contributions and addressing their concerns. Healthcare professionals should ensure that patients and carers have access to timely, pertinent information tailored to their level of understanding and needs. Healthcare professionals should also recognise that there are other available sources of support and sign-post carers to these.

9.2.3 Recommendations: Patients

The findings revealed that healthcare professionals frequently failed to identify patients who were isolated and had no-one to fulfil the carer role. This had serious implications because these patients were potentially vulnerable, at risk of becoming seriously ill at home with no-one to help them. Healthcare professionals should always assess what support the patient has at home. However, patients have a right to autonomy and confidentiality (NMC, 2008). Therefore, in agreement with the GMC guidance (2009) and Worthington et al (2013) patients should always be asked for their consent before any information is shared with those who support them. However, while they are receiving chemotherapy patients should recognise that they may have to rely on family members or friends. Healthcare professionals have an important role to play by providing 'permission' for carers to be involved, which in turn may help both patients and carers support each other more effectively. Practitioners can do this by explaining to patients that the service recognises the importance of having someone to help them at home during chemotherapy and that these people may also need guidance and support to help them. They should help the patient at the start of treatment identify who is likely to provide this support.

Similar to the findings of this study, recent guidance published by Macmillan (2014) strongly recommends that healthcare professionals avoid using terms such as 'carers' and 'caring', and instead use words such as 'those who will support you at home'.

9.2.4 Recommendations: Healthcare Organisations

The findings demonstrated that involving carers in patients' care is complex and challenging for healthcare professionals. This needs to be recognised by those leading healthcare organisations. Enabling staff to provide person-centred and safe care, which meets the needs of both patients and carers, requires change at every level of the system. While a transformational organisation approach is needed (section 8.7), it is acknowledged that change is more likely to be embedded within an organisation if an incremental approach is followed building on successes however, small (NPSA, 2013).

The following recommendations for enhancing support for carers in the acute cancer setting are in consonance with Worthington et al's (2013) guide to best practice for involving carers in the acute mental health care service and recently published guidance from Macmillan Cancer Support (2014).

- The findings of this study demonstrated that support for carers should not just be seen as an add-on but as essential component of person-centred care. This should be reflected within a collectively agreed philosophy of the service.
- Organisations should ensure that the environment welcomes and recognises carers, e.g. provide comfortable chairs and easily accessible information leaflets (Macmillan, 2014).
- Healthcare organisations need to establish protocols and practical guidelines, which clarify how the service expects practitioners to work with carers.
- There should be a designated person, as outlined by the NICE (2004) supportive care guidelines, whose defined role is to raise awareness and champion the needs of carers within the service and who can lead on service-wide initiatives and training for staff.
- The findings revealed that healthcare professionals were often uncertain about what resources were available for patients and carers. Therefore, the availability of supportive care resources for carers (and patients) inside and outside the service should be identified, disseminated to all staff and regularly up-dated.

9.2.5 Recommendations: Policy Makers and Professional Bodies

Policy makers and professional bodies also need to recognise that supporting carers in acute settings can be complex and challenging for healthcare professionals. Those leading at decision-making levels must ensure that services have the necessary resources and guidelines to meet the current aspirations of healthcare policy. Professional bodies, such as the NMC and RCN, also have a crucial leading role in enabling person-centred care, which incorporates the needs of carers, in clinical practice. As outlined in the discussion chapter, there is limited professional guidance on the expectations and parameters for involving carers, yet, there needs to be. Issues of patient confidentiality, for example, must be clarified. Furthermore, it has been over a decade since the NICE (2004) guidelines for improving supportive and palliative care for adults with cancer were written. These should be reviewed and revised incorporating all that has been learnt since these guidelines were initially published.

9.3 Implications for the Healthcare Research Community

This study has raised some important implications for the research community. Some of these have been highlighted within the very recent MRC (2014) guidance for process evaluation of complex interventions. Previously research-developed interventions for carers in the acute cancer setting have failed to be translated into practice. What is not clear is whether the interventions failed because they were not fit for purpose or due to poor implementation. This then makes it very difficult for policy-makers, other researchers and practitioners to identify potentially useful interventions and understand how to improve those that were not effective. Researchers must endeavour to report all the processes involved, including how the intervention was delivered and by whom, when publishing intervention studies (Mohler, et al, 2012).

However, the findings of this study have clearly demonstrated that practitioners experience significant challenges when addressing the needs of carers within the complex and busy environments in which they work. Indeed the policy and service aspirations for providing better support for carers are in danger of becoming a 'wicked problem' (Grint, 2008). The MRC (2014, p. 19) state that all developed interventions '*represent attempts to implement a course of action in order to address a perceived problem*'. In this study the problems were multifactorial and complex. This needs to be recognised by researchers who are developing interventions for carers.

Researchers should underpin intervention development work with theories of implementation and management of change (MRC, 2008). The most important factor is to involve those who will deliver or be recipients of the interventions to ensure that the interventions are feasible and meaningful. Researchers have an obligation to adopt an engaged scholarship approach (Van de Ven, 2007). Research needs to take place in practice with practitioners to enable them to have ownership of the problems and the changes that are instigated. It also needs to be recognised that interventions to prepare and support carers do not necessarily have to be complicated. It is however, complex to implement change within busy clinical settings. Carers do not exist in isolation, interventions that are developed need to consider all those that the intervention may impact upon. Introducing change inevitably creates anxiety and uncertainties (NHS, 2005; Shanley, 2007). Therefore, the emotional impact must be acknowledged and practitioners should be supported by researchers.

Robust evidence is required to drive, support and sustain efforts to embed person-centred care (including meeting carers' needs) in practice. The findings of this study indicate that developing one-off interventions will not work. Researchers must engage with practitioners at every level and actively listen to the 'real world' problems they are faced with. Using methodologies, such as action research, can enable researchers and practitioners to develop collaboratively practice and find strategies for managing the very challenging nature of healthcare professionals' work.

9.3.1 Further Research

The findings of this study have clearly identified a number of areas which require further research. This includes:

- To explore how best to identify and support isolated patients.
- Carers from BME groups were difficult to recruit and it was not clear why.
- More research is required to explore and gain consensus on the terminology used to describe those who support patients at home.
- Issues of patient confidentiality and sharing information with carers require further exploration, especially from patients' perspectives.
- More research is required for identifying and determining effective methods for enabling and supporting practitioners to manage the uncertain and complex nature of their work.

9.4 Final Conclusions

There appears to be an assumption in policy, research and professional codes of practice that healthcare professionals will simply be able to deliver support to carers. The findings have demonstrated that this is clearly not the case. However, carers who adopted essential roles had relatively simple needs. They did not require particularly complex interventions. What carers needed were healthcare professionals (predominately nurses) and the service to be aware and mindful of their roles and needs, and have the ability to acknowledge and manage difficulties and sign-post when necessary to other sources of support. Yet, involving carers required nurses to engage with more potentially difficult and challenging work for which they had little organisational and professional support.

Using participatory methods this research demonstrated that participants became more aware of the problems, which prevented patients and carers from being supported and find solutions themselves to address these problems. In doing so, the participants in this study will not have changed the world, as the quote at the beginning of this chapter suggests, they may though, have changed the world for some patients and carers, and perhaps more importantly for themselves. However, this research has demonstrated that if healthcare professionals are to fulfil the current political and NHS ambitions of person-centred care, which incorporates carers' needs, then they must have the practical guidance, support and resources to do so. An integrated approach, unifying policy, education, the organisation and multi-disciplinary team needs to be established.

References

Adams E. Boulton M. and Watson E. (2009) The information needs of partners and family members of cancer patients: A systematic literature review. Patient Education and Counselling, 77, pp. 179-186.

Adler N.E. and Page A.E.K. (2008) Cancer care for the whole patient: meeting psychosocial health needs. Washington (DC) National Academies Press. (USA).

Allen D. (2004) Ethno-methodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. Nursing Inquiry, 11 (1), pp. 14-24.

Allen D. (2010) Fieldwork and Participation. In Bourgeault I. Dingwall R. and De Vries R. (eds.) The Sage Handbook of Qualitative Methods in Health Research. Los Angeles, Sage.

Allan H. (2001) A ‘good enough’ nurse: supporting patients in a fertility unit. Nursing Inquiry, 8, pp.51-60.

Argyle C. (2013) Heading for a caring crisis. Cancer Nursing Practice. 12 (10), p. 11.

Argyris C. (1976) Single-loop learning and double loop models in research on decision making. Administrative Science Quarterly, 21 (3) pp. 363-375.

Argyris C. and Schon D. (1974) Theory in practice: Increasing professional effectiveness. San Francisco: Jossey Bass.

Argyris C. and Schon D. (1978) Organisational learning: A theory of action perspective. Reading, Massachusetts: Addison Wesley.

Argyris C. and Schon D. (1991) Participatory Action Research and Action Science Compared. In Whyte W.F. (ed.) Participatory Action Research. Newbury Park, Sage.

Arksey H. and O’Malley L. (2005) Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8 (1), pp. 19-32.

Armstrong R. Hall B.J. Doyle J. and Waters E. (2011) Cochrane update: ‘scoping the scope’ of a Cochrane review. Journal of Public Health, 33 (1), pp. 147-150.

Attree P. Morris S. Payne S. Vaughan S. and Hinder S. (2010) Exploring the influence of service involvement on health and social care services for cancer. Health Expectations, 14, pp. 48-48.

Aveyard H. (2010) Doing a Literature Review. Maidenhead, Open University Press.

Bain A. (1998) Social defences against organisational learning. Human Relations, 51, pp. 413-429.

Baker R. Camosso-Stefinovic J. Gillies C. Shaw E.J. Cheater F. Flottorp S. and Robertson N. (2010) Tailored interventions to overcome identified barriers to change: effects on professional practice and health care outcomes. The Cochrane Collaboration. DOI: 10.1002/14651858.CD005470.pub2

Baker S.E. and Edwards R. (2012) How many qualitative interviews is enough? University of Southampton, National Centre for Research Methods Review Paper.

Bandura A. (1997) Self-Efficacy: The Exercise of Control. New York, Freeman.

Barge J.K. and Shockley-Zalabak P. (2008) Engaged scholarship and the creation of useful organisational knowledge. Journal of Applied Communication Research, 36 (3), pp. 251-265.

Bar-On R. (2000) The Handbook of Emotional Intelligence: the theory and practice of development, evaluation, education and implementation: at home, school and the workplace. San Francisco, Jossey Bass.

Bennett F. (2012) Image of nurse spinning plates. Accessed Nov 2012.
http://www.felixbennett.com/portfolio/viewprint.asp?imageid=103

Benson J. and Britten N. (1996) Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semi-structured interviews with patients. British Medical Journal, 313, p. 729.

Berkof M. van Rijssen H.J. Schellart A.J.M. Anema J.R. and van der Beek A.J. (2011) Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews. Patient Education and Counselling, 84 pp. 152-162.

Bevan J.L. and Pecchioni L.L. (2008) Understanding the impact of family caregiver cancer literacy on patient health outcomes. Patient Education and Counselling, 71, pp. 356-364

Blackwood B. (2006) Methodological issues in evaluating complex healthcare interventions. Journal of Advanced Nursing, 54 (5), pp. 612-621.

Blackwood B. O'Halloran P. and Porter S. (2010) On the problem of mixing RCTs with qualitative research: the case of the MRC framework for the evaluation of complex healthcare interventions. Journal of Research in Nursing, 15 (6), pp. 511-521.

Blum K. and Sherman D.W. (2010) Understanding the experience of caregivers: a focus on transitions. Seminars in Oncology Nursing, 26 (4), pp. 243-258.

Bodenmann G. (2005). Dyadic Coping and its Significance for Marital Functioning. In Revenson T.A. Kayser K. and Bodenmann G. (eds.), Couples Coping with Stress: Emerging Perspectives on Dyadic Coping. Washington, DC. American Psychological Association.

Bonner A. and Tolhurst G. (2002) Insider-outsider perspectives of participant observation. Nurse Researcher, 9 (4), pp. 7-4.

Boothroyd L. and Lehoux P. (2004) Home-Based Chemotherapy for Cancer: Issues for Patients, Caregivers, and the Health Care System. Report: Agence d'Evaluation des Technologies et des Modes d'Intervention en Santé (AETMIS) Montréal, pp. xvi-77.

Bowen M. (1978) Family Therapy in Clinical Practice. New York, Jason Aronson.

Bowling A. (2009) Research methods in health. Maidenhead, Open University Press.

Bradbury P. and Reason H. (2001) Conclusion: Broadening the Bandwidth of Validity: Issues and Choice-points for Improving the Quality of Action Research. In Reason P. and Bradbury H. (eds.) Handbook of Action Research: Participative Inquiry and Practice. London, Sage Publications.

Bradley F. Wiles R. Kinmonth A.L. Mant D. and Gantley M. (1999) Development and evaluation of complex interventions in health services research: case study of the Southampton heart integrated care project (SHIP). British Medical Journal, 318, pp. 711-715.

Bradshaw T. Lovell K. Bee P. and Campbell M. (2010) The development and evaluation of a complex health education intervention for adults with a diagnosis of schizophrenia. Journal of Psychiatric and Mental Health Nursing, 17, pp. 473-486.

Bradshaw T. Wearden A. Marshall M. Warburton J. Husain N. Pedley R. Escott D. Swarbrick C. and Lovell K. (2012) Developing a healthy living intervention for people with early psychosis using the Medical Research Council's guidelines on complex interventions: Phase 1 of the HELPER – InterACT programme. International Journal of Nursing Studies, 49, pp. 398-406.

Brain J. Schofield J. Gerrish K. Mawson S. Mabbott I. Patel D. and Gerrish P. (2011) A Guide for Clinical Audit, Research and Service Review. An educational toolkit designed to help staff differentiate between clinical audit, research and service review activities. Healthcare Quality Improvement Partnership.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101.

Breen L.J. (2007) The researcher 'in the middle': Negotiating the insider/outsider dichotomy. The Australian Community Psychologist, 19 (1), pp. 163-174.

Brennan J. (2004) Cancer in Context: A Practical Guide to Supportive Care. Oxford, Oxford University Press.

Brett J. Staniszewska S. Mockford C. Herron-Marx S. Hughes J. Tysall C. and Suleman R. (2012) Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expectations, doi:10.1111/j.1369.2012.00795.x

Bridges W. (2004) Transitions Making Sense of Life's Changes. Cambridge, USA, Da Capo Press.

Bridges W. (2009) Managing Transitions: Making the Most of Change. 3rd Edition. London, Nicholas Brealey Publishing.

Bridges J. Nicholson C. Maben J. Pope C. Flatley M. Wilkinson C. Meyer J. and Tziggili M. (2013) Capacity for care: Meta-ethnography of acute care nurses' experiences of the nurse-patient relationship. Journal of Advanced Nursing, 69 (4), pp. 760–772.

Brien S.E. Lorenzetti D.L. Lewis S. Kennedy J. and Ghali W.A. (2010) Overview of a formal scoping review on health system report cards. Implementation Science, 5 (2), accessed 23/6/13 www.implemetationscience.com/content/5/2/1

Brown J. (1999) Bowen Family Systems Theory and Practice: Illustration and Critique. Australian and New Zealand Journal of Family Therapy (ANZJFT), 20 (2) pp. 94-103.

Brown V. Cotterell P. Sitzia J. Richardson A. Kelley K. and Willers R. (2006) Review of the literature on service user and carer involvement in England: An evaluation of consumer research panels in cancer research networks. London, Macmillan Cancer Support.

Brown M. and Stetz K. (1999) The labour of caregiving: A theoretical model of caregiving during potentially fatal illness. Qualitative Health Research, 9 (2), pp. 182-197.

Bryman A. (2008) Social Research Methods. Oxford, Oxford University Press.

Burgess C.C. Bish A.M. Hunter H.S. Salkovskis P. Michell M. Whelehan P. and Ramirez A.J. (2008) Promoting early presentation of breast cancer: development of a psycho-educational intervention. Chronic Illness, 4, pp. 13-27.

Burgess C.C. Linsell L. Kapari M. Omar L. Michell M. Wheelhan P. Richards M.A. and Ramirez A.J. (2009) Promoting early presentation of breast cancer by older women: A preliminary evaluation of a one-to-one health professional-delivered intervention. Journal of Psychosomatic Research, 67, pp. 377-387.

Burgess C.C. Ramirez A.J. Richards M.A. and Love S.B. (1998) Who and what influences delayed presentation to breast cancer? British Journal of Cancer, 77 (8), pp. 1343-1348.

Burgess C. Teasdale E. Omar L. Tucker L. and Ramirez A.J. (2012) Training Radiographers to deliver an intervention to promote early presentation of breast cancer. Radiography, 18, pp. 232-237.

Burridge L. Winch S. and Clavarino A. (2007) Reluctance to care. A systematic review and development of a conceptual framework. Cancer Nursing. 30, (2), pp. E9-E19.

Cabana M.D. Rand C.S. Powe N.R. Albert W.W. Wilson M.H. Abboud P.C. and Rubin H.R. (1999) Why don’t physicians follow clinical practice guidelines? A framework for improvement. JAMA, 282 (15), pp. 1458-1466.

Campbell M. Fitzpatrick R. Haines A. Kinmouth A.L. Sandercock P. Spielgelhalter D and Tyler P (2000) Framework for design and evaluation of complex interventions to improve health. British Medical Journal, 321, pp. 694-696.

Campbell N.C. Murray E. Darbyshire J. Emery J. Farmer A. Griffiths F. Guthrie B. Lester H. Wilson P. and Kinmonth A.L. (2007) Designing and evaluating complex interventions to improve health care. British Medical Journal, 334, pp. 455-459.

Cane J. O’Connor D. and Michie S. (2012) Validation of the theoretical domains framework for use in behaviour change and implementation of research. Implementation Science. 7:37.

Carers UK. (2011) Valuing Carers 2011: Calculating the value of carers’ support. London, Carers UK.

Carers UK. (2013) Prepared to Care? Exploring the impact of caring on people’s lives. London, Carers UK.

Caress A.L. Chalmers K. and Luker K. (2009) A narrative review of interventions to support family carers who provide physical care to family members with cancer. International Journal of Nursing Studies, 46, pp. 1516-1527.

CASP (2006) 10 questions to help you make sense of reviews. Critical Appraisal Skills Programme, England, Public Health Resource Unit.

Cella D, Tulsky D, Gray G, Sarafian B. Linn E. Bonomi A. Silberman M. Yellen S.B. Winicour P. and Brannon J. (1993) The Functional Assessment of Cancer Therapy Scale: development and validation of the general measure. Journal Clinical Oncology, 111, pp. 570-579.

Chatham House (2013) Chatham House Rule. Accessed 12/10/13 http://www.chathamhouse.org/about-us/chathamhouserule

Cherry M.G. Fletcher I. Shaw N. and O'Sullivan H. (2012) What impact do structured educational sessions to increase emotional intelligence have on medical students? Medical Teacher 34 issue 1, pp. 11-19

Cohen-Fineberg I. Kawashima M. and Asch S.M. (2011) Communication with families facing life-threatening illness: a research-based model for family conferences. Journal of Palliative Medicine. 14 (4), pp. 421-427.

Collins A. (2014) Measuring what really matters. London, The Health Foundation.

Collins S. Britten N. Ruusuvuori J. and Thompson A. (2007) Patient Participation in Health Care Consultations. Maidenhead, Berkshire, Oxford University Press.

Colbourne L. (2008) The experience of treatment. In Corner J. and Bailey C. (eds.) Cancer Nursing: Care in Context. Blackwell Publishing, Oxford.

Coombs M. Latter S. and Richardson A. (2012) Developing a clinical academic career pathway for nursing. British Journal of Nursing, 21 (18), pp. 1088-90.

Conn V.S. (2007) Editorial: Intervention? What intervention? Western Journal of Nursing Research, 29 (5), pp. 521-522.

Connolly M. Perryman J. McKenna Y. Orford J. Thomson L. Shuttleworth J. Cocksedge S. (2009) SAGE & THYME: A model for training health and social care professionals in patient-focused support. Patient Education and Counselling, 79 (1) pp. 87-93

Cook T. (2012) Where participatory approaches meet pragmatism in funded (health) research: The challenge of finding meaningful spaces. Forum: Qualitative Social Research, 13 (1).

Couper J. Bloch S. Love A. Macvean M. Duchesne G.M. and Kissane D. (2006) Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. Pyshco-Oncology, 15, pp. 937-953.

Cowley L. Heyman B. Stanton M. and Milner S.J. (2000) How women receiving adjuvant chemotherapy for breast cancer cope with their treatment: a risk management perspective. Journal Advanced Nursing, 31(2), pp. 314-321.

Craig P. Dieppe P. Macintyre S. Michies S. Nazareth I. and Petticrew M. (2008) Developing and Evaluating Complex Interventions: The new Medical Research Council Guidance. British Medical Journal, 337, pp. 979-983.

Cresswell J.W. (2009) Research Design: Qualitative, Quantitative and Mixed Methods Approaches. Thousand Oaks, USA, Sage.

Cresswell J.W. (2013) Qualitative Inquiry and Research Design: Choosing Among Five Approaches. Los Angeles, Sage.

Davies P. Walker A.E. and Grimshaw J.M. (2010) A systematic review of the use of theory in the design of guideline dissemination and implementation strategies and interpretation of the results of rigorous evaluations. Implementation Science, 5:14. Open Access, accessed 1/11/12. www.implementationscience.com/content/5/1/14

Deeken J.F. Taylor K. Mangan P. Yabroff K.R. and Ingham J.M. (2003) Care for the caregivers: A review of self-report instruments developed to measure the burden, needs and quality of life of informal caregivers. Journal of Pain and Symptom Management, 26 (4), pp. 922-953.

De Jong G. Horn S.D. Gassaway J.A. Slavin M.D. and Dijkers M.P. (2004) Toward a taxonomy of rehabilitation interventions: Using an inductive approach to examine the "Black Box" of rehabilitation. Archives of Physical Medicine and Rehabilitation, 85, pp. 678-686.

Denis J.L. and Lomas J. (2003) Convergent evolution: the academic and policy roots of collaborative research. Journal of Health Services Research and Policy, 8, (1), pp. S2:1-6.

Denscombe M. (2010) The Good Research Guide. Maidenhead, Open University Press.

Department of Health (1995a) What next for carers? Findings from a social services inspectorate project. Social Services Inspectorate, London. The Stationary Office.

Department of Health (1995b) A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. A Policy Framework for Commissioning Cancer Services: The Calman–Hine Report. London. The Stationary Office.

Department of Health (1995c) Carers (Recognition and Services) Act: Policy Guidance. London, The Stationary Office.

Department of Health (1999) Caring for Carers: A national strategy. London, The Stationary Office.

Department of Health (2005a) Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004. London, The Stationary Office.

Department of Health (2005b) Creating a Patient-Led NHS: Delivering the NHS Improvement Plan. London, The Stationary Office.

Department of Health (2006) Best Research for Best Health: A New National Health Research Strategy. The Stationary Office.

Department of Health (2007) Cancer Reform Strategy. London. The Stationary Office.

Department of Health (2008a) Carers at the Heart of 21st Century Families and Communities. London. The Stationary Office.

Department of Health (2008b) High Quality Care for All: NHS Next Stage Review Final Report. London, The Stationary Office.

Department of Health (2010a) Chemotherapy Services in the Community: A Guide for PCTs. London, The Stationary Office.

Department of Health (2010b) Recognised, Valued and Supported: Next steps for the Carers Strategy. London, The Stationary Office

Department of Health (2010c) National Cancer Survivorship Initiative. London, The Stationary Office.

Department of Health (2011) Improving Outcomes: A Strategy for Cancer. London, The Stationary Office.

Department of Health (2013) The Care Bill Factsheets. Accessed 12/12/12
https://www.gov.uk/government/publications/the-care-bill-factsheets

Deshields T.L. Rihanek A. Potter P. Zhang Q. Kuhrik M. Kuhrik N. and O'Neill J. (2011) Pyschosocial aspects of caregiving: perceptions of cancer patients and family caregivers. Supportive Cancer Care. DOI 10.1007/s00520-011-1092-1.

Dickens L. and Watkins K. (1999) Action research: Rethinking Lewin. Management Learning, 30 (2), pp. 127-140.

Dixon-Woods M. Agarwal S. Jones D. Young B. and Sutton A. (2005) Synthesising qualitative and quantitative evidence: a review of possible methods. Journal of Health Service Research Policy, 10 (1), pp. 45-53.

Dixon-Woods M. Baker R. Charles K. Dawson J. Jezembek G. Martin G. McCarthy I. McKee L. Minion J. Ozieranski P. Willars J. Wilkie P. and West M. (2013) Culture and behaviour in the English National Health Service: overview of lessons from a large multi-method study. BMJ Quality and Safety. Doi 10.1136/bmjqs-2013-001947.

DuBenske L.L. Chih D.H. Gustafon D.H. Dinauer S. and Cleary J.F. (2010) Caregivers' participation in the oncology clinic visit mediates the relationship between their information competence and their need fulfilment and clinic visit satisfaction. Patient Education and Counselling, 81S, pp. S94-S99.

Dunleavy P. (2003) Authoring a PhD. London, Palgrave Macmillan.

Durlak J.A. and DuPre E.P. (2008) Implementation Matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. American Journal of Community Psychology, 41, pp. 327-250.

Eccles M. Grimshaw J. Walker A. Johnston M. and Pitts N. (2005) Changing the behaviour of healthcare professionals: the use of theory in promoting the uptake of research findings. Journal of Clinical Epidemiology, 58, pp. 107-112.

Edmonstone J. (2013) Personal Resilience for Healthcare Staff: When the going gets tough. London, Radcliffe Publishing.

Eggly S. Penner L.A. Hagiwara N. Gonzalex R. Harper F.W.K. Heath E.I. and Albrecht T.L. (2013) Patient, companion and oncologist agreement regarding information discussed during triadic oncology clinical interactions. Psycho-Oncology 22, pp. 637-645.

Ekeland A.G. Bowes A. and Flottorp S. (2010) Effectiveness of telemedicine: a systematic review of reviews. International Journal of Medical Informatics, 79 (11), pp. 736-71.

Entwistle V.A. Renfrew M.J. Yearley S. Forrester J. and Lamont T. (1998) Lay perspectives: advantages for health research, British Medical Journal, 316, p. 463.

Epstein R.M. and Street R.L. (2007) Patient-Centred Communication in Cancer Care: Promoting Healing and Reducing Suffering. USA, National Cancer Institute.

Eriksson E. (2001) Caring for cancer patients: relatives' assessments of received care. European Journal of Cancer Care, 10, pp. 48-55.

Farquhar M. Higginson I.J. Fagan P. and Booth S. (2010) Results of a pilot investigation into a complex intervention for breathlessness in advanced chronic obstructive pulmonary disease (COPD): Brief Report. Palliative and Supportive Care, 8, pp.143-149.

Farrell C. Heaven C. Beaver K. and Maguire P. (2005) Identifying the concerns of women undergoing chemotherapy. Patient Education and Counselling, 56, pp. 72-77.

Farrell C. Molassiotis A. Beaver K. and Heaven C. (2011) Exploring the scope of oncology specialist nurses' practice in the UK. European Journal of Oncology Nursing 15, pp. 160-166.

Ferrell B.A. Grant M. Schmidt G.M. et al. (1992) The meaning of quality of life for bone marrow transplant survivors. Part 1: The impact of bone marrow transplant on quality of life. Cancer Nursing, 15, pp. 153-160.

Fetterman D.M (2010) Ethnography: Step by Step. Applied Social Research Methods Series. Thousand Oaks, USA, Sage

Firth P. (2006) Patients and their Families. In Stiefel F. (vol. ed.) Communication in Cancer Care. Schlag P.M and Senn H.J. (series eds.) Recent Results in Cancer Research. New York, Springer.

Fishbein M. (2000) The role of theory in HIV prevention. Aids Care, 12 (3), pp. 273-278.

Fitch M. (2000) Supportive Care for Cancer Patients. Hospital Quarterly, Summer, pp. 39-46.

Folkman S. and Lazarus R.S. (1985) If it changes it must be a process: study of emotion and coping during three stages of a college examination. Journal of Personality and Social Psychology, 48 (1), pp. 150-170.

Fook J. (2006) Critical reflection: a review of contemporary literature and understandings. In White S. Fook J. and Gardner F. (eds.) Critical Reflection in Health and Social Care. Maidenhead, Berkshire, Open University Press.

Forbes A. (2009) Clinical intervention research in nursing. International Journal of Nursing Studies, 46 pp. 557-568.

Forbes A. and Griffiths P. (2002) Methodological strategies for the identification and synthesis of 'evidence' to support decision-making in relation to complex healthcare systems and practices. Nursing Inquiry, 9, pp. 141-155.

Forbes L.J.L. Linsell L. Atkins L. Burgess C. Tucker L. Omar L. and Ramirez A.J. (2011) A promoting early presentation intervention increases breast cancer awareness in older women after 2 years: a randomised controlled trial. British Journal of Cancer, 105, pp. 18-21.

Fortin VI A.H. Dwamena F.C. Frankel R.M. and Smith R.C. (2012) Smith's Patient-Centred Interviewing: An evidence-based method. New York, McGraw Hill Medical.

Fox M. Martin P. and Green G. (2007) Doing Practitioner Research. London, Sage Publications Ltd.

Francis J.J. Stockton C. Eccles M.P. Johnston M. Cuthbertson B.H. Grimshaw J.M. Hyde C. Tinmouth A. and Stanworth S.J. (2009) Evidence-based selection of theories for designing behaviour change interventions: using methods based on theoretical construct domains to understand clinicians' blood transfusion behaviour. British Journal of Health Psychology, 14, pp. 625-646.

Francis R. (Chair) The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary. London: Stationery Office.

Francke A.L. Smit M.C. de Veer A.J.E. and Mistiaen P. (2008) Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review. BMC Medical Informatics and Decision Making, 8:38 Open Access. Accessed 20/9/13.
www.biomedcentral.com/1472-6947-8-38

Fraser S.W. and Greenhalgh T. (2001) Coping with complexity: Educating for capability. British Medical Journal. 323, pp. 799-803.

Freire P. (1970) Pedagogy of the Oppressed. London, Penguin Books.

French S.D. Green S.E. O'Connor D.A. McKenzie J.E. Francis J.J. Michie S. Buchbinder R. Schattner P. Spike N. and Grimshaw J.M. (2012) Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. Implementation Science, 7:38. Accessed 22/7/13.
www.implementationscience.com/contents/7/1/38

Freshwater D. (2004) Emotional intelligence: developing emotionally literate training in mental health. Mental Health Practice, 8 (4), pp. 12-15.

Freshwater D. and Stickley T. (2004) The heart of the art: Emotional intelligence in nurse education. Nursing Inquiry, 11 (2), pp. 91-98.

Froggatt K. Heimerl K. and Hockley J. (2013) Challenges for Collaboration. In Hockley J. Froggatt K. and Heimerl K. (eds.) Participatory Research in Palliative Care: Actions and Reflections. Oxford, Oxford University Press.

Frost P.J. (2003) Toxic Emotions at Work. Boston, Harvard Business School Press.

Funk L. and Stajduhar K.I. (2010) Interviewing family caregivers: implications of the caregiving context for the research interview. Qualitative Health Research, 19(6), pp. 859-867.

Gallagher M. Hares T. Spencer J. Bradshaw C. and Webb I. (1993) The nominal group technique: A research tool for general practice. Family Practice, 10 (1), pp. 76-79.

Gelling L. and Munn-Giddings C. (2011) Ethical review of action research: the challenges for researchers and research ethics committees. Research Ethics, 7 (3), pp. 100-106.

General Medical Council (2009) Confidentiality: Guidance for Doctors. GMC. London.

Gibbs C. and Warhover T. (2002) Getting the Whole Story: Reporting and Writing the News. The Guildford Press, Guildford.

Gilbert E. Ussher J.M. Perz J. Hobbs K. and Kirsten L. (2010) Positive and negative interactions with healthcare professionals. A qualitative investigation of the experiences of informal cancer carers. Cancer Nursing, 33 (6), pp. E1-E9.

Gitlin L.N. (2013) Introducing a new intervention: An overview of research phases and common challenges. The American Journal of Occupational Therapy, 67 (2), pp. 177-184.

Glachen M. (2004) The emerging role and needs of family caregivers in cancer care. The Journal of Supportive Oncology. 2, pp. 145-155.

Gold M. Philip J. Mclver S. and Komesaroff P.A. (2009) Between a rock and a hard place: exploring the conflict between respecting the privacy of patients and informing their carers. Internal Medical Journal, 39, pp. 582-587.

Goleman D. (1998) Working with Emotional Intelligence. New York, Bantam Books.

Goodrich J. (2012) Supporting hospital staff to provide compassionate care. Do Schwartz Center Rounds work in English Hospitals? J.R. Soc Med. 105 (3) pp. 117-122.

Goodrich J. and Cornwell J. (2008) Seeing the person in the patient: the point of care review paper. London, The King's Fund.

Gough D. Thomas H. and Oliver S. (2012) Clarifying differences between review designs and methods. Systematic Reviews, Biomed Central. Accessed 19/11/13
www.systematic reviewsjournal.com/content/1/1/28

Graham I.D. Logan J. Harrison M.B. Straus S.E. Tetroe J. Caswell W. and Robinson N. (2006) Lost in knowledge translation: time for a map? The Journal of Continuing Education in the Health Professions, 26, pp. 13–24.

Grant M.J. and Booth A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. Health Information and Libraries Journal, 26, pp. 91-108.

Gray B. (2009) The emotional labour of nursing: Defining and managing emotions in nursing work. Nurse Education Today, 29 (2), pp. 168-175.

Gray B. Robinson C. Seddon D. and Roberts A. (2008) ‘Confidentiality smokescreens’ and carers for people with mental health problems: The perspectives of professionals. Health and Social Care in the Community, 16 (4), pp. 378-387.

Green J. and Thorogood N. (2009) Qualitative Methods for Health Research. London, Sage Publications.

Greenhalgh T. Robert G. Macfarlane P. Bate P. and Kyriakidou O. (2004) Diffusion of innovations in service organisations: systematic review and recommendations. The Millbank Quarterly, 82 (4), pp. 581-629.

Greenwood D.J. Foote Whyte W. and Harkavy I. (1993) Participatory action research as a process and as a goal. Human Relations, 46 (2), pp. 175-191.

Grewal D. and Salovey P. (2005) Feeling smart: the science of emotional intelligence. American Scientist, 93, pp. 330-339.

Grint K. (2008) Wicked problems and clumsy solutions: the role of leadership. Clinical Leader, 1 (2), pp. 54-68.

Grinyer A. (2006) Caring for a young adult with cancer: the impact on mothers’ health. Health and Social Care in the Community, 14 (4), pp.311-318.

Grol R. Bosch C. Hulscher M. Eccles M. and Wensing M. (2007) Planning and studying improvement in patient care: The use of theoretical perspectives. The Milbank Quarterly, 85 (1), pp. 93-138.

Grol R. and Grimshaw J. (2003) From best evidence to best practice: effective implementation of change in patients’ care. The Lancet, 362 pp. 1225-30.

Grol R. and Wensing M. (2004) What drives change? Barriers to and incentives for achieving evidence-based practice, Med. J. Aust. 180, S57–S60

Grol R. Wensing M. Eccles M. and Davis D. (2013) Improving patient care: The implementation of change in health care. Chichester, John Wiley and Sons.

Grundy S. and Kemmis S. (1981) Educational action research in Australia: The state of the art (an overview). Paper presented at the Annual Conference of the Australian Association for Research in Education, Adelaide, November 1981. In Kemmis S. and McTaggart R. (eds.) (1988) The Action Research Reader. Deakin, Australia, Deakin University Press.

Grundy S. (1982) Three modes of action research. Curriculum Perspectives. 2 (3), pp. 23-34. In Kemmis S. and McTaggart R. (eds.) (1988) The Action Research Reader. Deakin, Australia, Deakin University Press.

Guba E.G. (1990) The Alternative Paradigm Dialog. Newbury Park CA. Sage.

Guba E.G. and Lincoln Y.S. (1989) Fourth Generation Evaluation. Newbury Park, CA. Sage Publications.

Habermas J. (1972) Knowledge and Human Interests. London, Heinemann.

Hack T.F. Carlson L. Butler L. Degner L.F. Jakulj F. Pickles T. Reuther J.D. and Weir L. (2011) Facilitating the implementation of empirically valid interventions in psychosocial oncology and supportive care. Supportive Cancer Care, 19 (8), pp. 1097-105.

Hallowell N. Lawton J. and Gregory S. (2005) Reflections on Research: The Realities of Doing Research in the Social Sciences. Maidenhead, Open University Press.

Harden A. and Thomas J. (2011) Methodological Issues in Combining Diverse Study Types in Systematic Reviews. International Journal Social Research Methodology, 8, (3), pp. 257-271.

Harden J. (2005) Developmental Life Stage and Couples' Experiences with Prostate Cancer. Cancer Nursing, 28 (2), pp. 85-98.

Harding R. and Higginson I.J. (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. Palliative Medicine, 17, pp.63-74.

Harding R. Higginson I. J. Leam C. Donaldson N. Pearce A. and George, R. (2004) Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service. Journal of Pain and Symptom Management, 27 (5), pp. 396-408.

Harding R. List S. Epiphaniou E. and Jones H. (2011) How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. Palliative Medicine, 26 (1), pp. 7-22.

Hardwick C. and Lawson N. (1995) The information and learning needs of the caregiving family of the adult patient with cancer. European Journal of Cancer Care, 4, pp. 118-121.

Harper-Wynne and Kelly C.M. (2013) Chemotherapy. In: Palmieri C. Bird E. and Simcock R. (eds.) ABC of Cancer Care. Chichester, BMJ Books, Wiley Blackwell.

Harrison J.D. Young J.M. Price M.A. Butow P.N. and Solomon M.J. (2009) What are the unmet supportive care needs of people with cancer? A systematic review. Supportive Care Cancer, 17, pp. 1117-1128.

Hart E. and Bond M. (1995) Action Research for Health and Social Care. Open University Press, Buckingham.

Hart E. and Bond M. (1996) Making sense of action research through the use of a typology. Journal of Advanced Nursing, 23, pp. 152-159.

Hawker S. Payne S. Kerr C. Hardey M. and Powell J. (2002) Appraising the evidence: Reviewing Disparate Data Systematically. Qualitative Health Research, 12 (9), pp. 1284-1299.

Hayes J. (2010) The Theory and Practice of Change Management. Basingstoke, Palgrave Macmillan.

Hayter M. (2013) The UK Francis Report: the key messages for nursing. Journal of Advanced Nursing, 69: e1–e3.

Heaven C. Clegg J. and Maguire P. (2006) Transfer of communication skills training from workshop to workplace: The impact of clinical supervision. Patient Education and Counselling, 60, pp. 313-325.

Hendry C. (1996) Understanding and creating whole organisational change through learning theory. Human Relations, 49 (5), pp. 621-641.

Heron C. (1998) Working with Carers. London, Jessica Kingsley Publishers.

Heron J. (2001) Helping the Client: A Creative Practical Guide. London, Sage Publications.

Hewitt M.E. Greenfield S. Stovall E. (2005) National Cancer Policy Board. From Cancer Patient to Cancer Survivor: Lost in Transition. Committee on Cancer Survivorship: Improving Care and Quality of Life; Washington, DC: National Academies Press.

Hochschild A (1979) Emotion Work, Feeling Rules and Social Structure. American Journal of Sociology, 85, 3, pp. 551-575.

Hochschild A (1983) The Managed Heart. Berkeley, Ca. University of California Press.

Hockley J. (2013) Critical Theory and Action Research. In Hockley J. Frogatt K. and Heimerl K. (eds.) Participatory Research in Palliative Care: Actions and Reflections. Oxford University Press.

Hockley J. and Froggatt K. (2006) The development of palliative care knowledge in care homes for older people: the place of action research. Palliative Medicine, 20, pp. 835-843.

Hockley J. Frogatt K. and Heimerl K. (2013) Participatory Research in Palliative Care: Actions and Reflections. Oxford, Oxford University Press.

Hodges L.J. Walker J. Kleiboer A.M. Ramirez A.J. Richardson A. Velikova G. and Sharpe M. (2010) What is a Psychological intervention? A meta-review and practical proposal. Psycho-Oncology, DOI: 10.1002/pon.1780.

Holbeche L. (2006) Understanding Change: Theory, Implementation and Success. London, Elsevier.

Holloway I. and Todres L. (2010) Ethnography. In Gerrish K. and Lacey A. (eds.) The Research Process in Nursing. Chichester, Wiley-Blackwell.

Honea N.J. Brintnall R.A. Given B. Sherwood P. Colao D.B. Somers S.C. and Northouse L.L. (2008) Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden. Clinical Journal of Oncology Nursing, 12 (3), pp. 507-516.

Hopkinson J.B. Brown J.C. and Addington-Hall J.M. (2012) The effectiveness of patient-family carer couple intervention for the management of symptoms and other health-related problems in people affected by cancer: A systematic literature search and narrative review. Journal of Pain and Symptom Management, 43 (1), pp. 111-142.

Houghton C. Casey D. Shaw D. and Murphy K. (2013) Rigour in Qualitative Case-Study Research. Nurse Researcher, 20 (4), pp.12-17.

Hubbard G. Backett-Milburn and Kemmer C. (2001) Working with emotion: Issues for the research in fieldwork and teamwork. International Journal of Social Research Methodology, 4 (2), pp. 119-137.

Hubbard G. Illingworth N. Rowa-Dewar N. Forbat L. and Kearney N. (2010) Treatment decision-making in cancer care: the role of the carer. Journal of Clinical Nursing, 19, pp. 2023-2031.

Hubbard G. Kidd L. Donaghy E. McDonald C. and Kearney N. (2007) A review of literature about involving people affected by cancer in research, policy and planning and practice. Patient Education and Counselling, 65, pp. 21-33.

Hudson P.L. Aranda S. and Kristjanson L.J. (2004) Meeting the supportive needs of family caregivers in palliative care: challenges for healthcare professionals. Journal of Palliative Medicine, 7 (1), pp. 19-25.

Hudson P.L. Aranda S. Hayman-White K. (2005) A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomised control trial. Journal of Pain and Symptom Management, 30 (4), pp.329-341.

Hudson P. Thomas T. Quinn K. Cockayne M. and Braithwaite M. (2009) Teaching family carers about home-based palliative care: Final results from a group education programme. Journal of Pain and Symptom Management, 38 (2), pp. 299-308.

Hudson P.L. Remedios C. and Thomas K. (2010) A systematic review of psychosocial interventions for family carers of palliative care patients. BMC Palliative Care. 9: 17. Accessed 5/5/11. http://www.biomedcentral.com/1472-684X/9/17 .

Hunter B. and Smith P. (2007) Emotional Labour: Just another buzz word? International Journal of Nursing Studies, 6, p 859-861.

Hurley J. (2012) Introducing Emotional Intelligence. In Hurley J. and Linsley P. (eds.) Emotional Intelligence in Health and Social Care: A Guide for Improving Relationships. London, Radcliffe Publishing Ltd.

Hurley J. and Linsley P. (2012) Emotional Intelligence in Health and Social Care: A Guide for Improving Relationships. London, Radcliffe Publishing Ltd.

Hutchinson A.M. and Johnston L. (2003) Bridging the divide: a survey of nurses' opinions regarding barriers to, and facilitators of, research utilisation in the practice setting. Journal of Clinical Nursing 13, pp. 304–315.

Huy Q.N. (1999) Emotional Capability, Emotional Intelligence and Radical Change, Academy of Management Review, 24, 2, pp. 325-345.

Iconomou G. Vagenakis A.G. and Kalofonos H.P. (2001) The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. Supportive Cancer Care, 9, pp. 591-596.

Iles V. and Sutherland K. (2001) Organisational Change. London, NCCSDO.

Illes V. and Vaughan-Smith (2009) Working in health care could be one of the most satisfying jobs in the world –why doesn't it feel like that? Paper from the 'Take it to the Limit' Learning Set, Accessed 7/06/14 http://www.reallylearning.com/Current_Projects/Learning_Sets/take-it-to-the-limit-report2.pdf

Institute of Medicine (2001) Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: The National Academies Press.

INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research. Eastleigh, INVOLVE.

James N. (1992) Care = organisation + physical labour + emotional labour. Sociology of Health and Illness, 14 (4), pp. 488-509.

Jarrett M. (2004) Tuning into the emotional drama of change: extending the consultant's bandwidth. Journal of Change, 4 (3) pp. 247-258.

Jasper M.A. (2005) Using reflective writing in research. Journal of Research in Nursing, 10 (3), pp. 247-260.

Kawulich B.B. (2005) Participant observation as a data collection method. Forum Qualitative Research, 6 (2).

Kayser K. Watson L.E. and Adrade J.T. (2007) Cancer as a "we-disease": Examining the process of coping from a relational perspective. Families, Systems and Health, 25 (4), pp. 404-418.

Kelly D. And Simpson S. (2001) Action research in action: reflections on a project to introduce Clinical Practice Facilitators to an acute hospital setting. Journal of Advanced Nursing, 33 (5), pp. 652-659.

Kemmis S. (1988) Action research in retrospect and prospect. In Kemmis S. and McTaggart R. (eds.) (1988) The Action Research Reader. Deakin, Australia, Deakin University Press.

Kernick D. (2011) Leading in complex environments. In Swanwick T. and Mckimm J. (eds.) ABC of Clinical Leadership. Chichester, John Wiley and Sons Ltd.

King J. (2011) Understanding yourself as leader. In In Swanwick T. and Mckimm J. (eds) ABC of Clinical Leadership. Chichester, John Wiley and Sons Ltd.

King M. Jones L. and Nazareth I. (2006) Concern and Continuity in the Care of Cancer Patients and their Carers: A Multi-Method Approach to Enlightened Management. Report for the National Co-Ordinating Centre for NHS Service Delivery and Organisation R&D. London, HMSO.

Kinnane N. A. and Milne D. J. (2010) The role of the internet in supporting and informing carers of people with cancer: a literature review. Supportive Cancer Care, 18, pp. 1123-1136.

Kipling R (1902) Just So Stories (1982). Purnell Books Ltd, London.

Kitrungrote L. and Cohen M.Z. (2006) Quality of life of family caregivers of patients with cancer: A literature review. Oncology Nursing Forum, 33 (3), pp. 625-632.

Kitson A.L. Harvey G. and McCormack B. (1998) Approaches to implementing research in practice. Quality in Health Centre, 7 (3), pp. 149-159.

Kitson A.L. Marshall A. Bassett K. and Zeitz K. (2012) What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. Journal of Advanced Nursing, 69 (1), pp. 4-15.

Koshy E. Koshy V. and Waterman H. (2011) Action Research in Healthcare, Sage, London.

Kristjanson L.J. and Ashcroft T. (1994) The family's cancer journey: A literature review. Cancer Nursing, 17 (1), pp. 1-17.

Laizner A.M. Shegda Yost L.M. Barg F.K. and McCorkle R. (1993) Needs of family caregivers of persons with cancer: A review. Seminars in Oncology Nursing, 9 (2), pp. 114-120.

Lambert S.D. Harrison J.D. and Smith E. (2012) The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Supportive Palliative Care published on-line July 6, 2012, doi: 10.1136/bmjspcare-2012-000226. Accessed 17/11/13

Lathlean J. (2010) Qualitative Analysis. In Gerrish K. and Lacey A. (eds.) The Research Process in Nursing. Chichester, Wiley-Blackwell.

Lazarus R.S. and Folkman S. (1984) Stress, Appraisal and Coping. New York, Academic Press.

Legare F. (2009) Assessing Barriers and Facilitators to Knowledge Use. In Straus S. Tetroe J. and Graham I.D. (eds.) Knowledge Translation in health Care: Moving from Evidence to Practice. Oxford, Wiley-Blackwell.

Legard R. Keegan J. and Ward K. (2003) In-depth interviews. Qualitative Research Practice. London, Sage Publications.

Lewin K. (1946) 'Action research and minority problems'. Journal of Social Issues, 2 (4), pp. 34-46. In Kemmis S. and McTaggart R. (eds.) (1988) The Action Research Reader. Deakin, Australia, Deakin University Press.

Lewin (1947) Frontiers in Group Dynamics. Human Relations, 1, pp. 5-41.

Lewin K. (1952) 'Group decision and social change'. In Kemmis S. and McTaggart R. (eds.) (1988) The Action Research Reader. Deakin, Australia, Deakin University Press.

Li Q.P. Mak Y.W. and Loke A.Y. (2013) Spouses' experiences of caregiving for cancer patients: a literature review. International Nursing Review, 60 (2) pp. 178-87.

Liberati A. Altman D.G. Tetzlaff J. et al. (2009) The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. PLoS Med.; 6: e1000100.

Lincoln Y.S. and Guba E.G. (1985) Naturalistic Enquiry. Beverly Hills, CA. Sage Publications.

Linsley P. and Carroll V. (2012) The therapeutic relationship and emotional intelligence. In Hurley J. and Linsley P. (eds.) Emotional Intelligence in Health and Social Care: A guide for improving relationships. London, Radcliffe Publishing Ltd.

Locke (2005) Why emotional intelligence is an invalid concept? Journal of Organizational Behaviour, 26, pp. 425-431.

Lofland J. Snow D. Anderson L. and Lofland L.H. (2006) Analysing Social Settings. 4th Edition. Belmont CA, USA. Wadsworth Cengage Learning.

Maben J. Cornwell J. and Sweeney K. (2010) In Praise of Compassion. Journal of Research in Nursing, 15 (1), pp. 9-13.

Maben J. Latter S. and Macleod Clark J. (2006) The theory-practice gap: impact of professional-bureaucratic work conflict on newly-qualified nurses. Journal of Advanced Nursing, 55 (4), pp. 465-477.

Mack N. Woodsong C. MacQueen K.M. Guest G. and Namey E. (2005) Qualitative Research Methods: A Data Collectors Field Guide. North Carolina, Family Health International.

Macmillan (2007) The future of cancer care: the views of people affected by cancer. London, Macmillan Cancer Support.

Macmillan (2008) Social Care for Cancer. London, Macmillan Cancer Support.

Macmillan (2011) More than a million. Understanding the UK's carers of people with cancer: A report by Ipsos Mori for Macmillan Cancer Support.

Macmillan (2014) Supporting Carers of People with Cancer: Practical Guidance for Healthcare Professionals. London, Macmillan Cancer Support.

Maddams J. Brewster D. Gavin A. Steward J. Elliott J. Utley M. and Møller H. (2009) Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer, 101, pp. 541-547.

Maguire P. Faulkner A. Booth K. Elliott C. and Hillier V. (1996) Helping cancer patients disclose their concerns. European Journal of Cancer. 32a (1), pp. 78-81.

Maher J. and McConnell H. (2011) New pathways of care for cancer survivors: adding the numbers. British Journal of Cancer, 105, S5-S10.

Manley K. et al (2011) Person-centred care: principle of nursing practice D. Nursing Standard, 25, 31, 35-37.

Manley K. Hardy S. Titchen A. Garbett R. and McCormack B. (2005) Changing patients' worlds through nursing expertise: A Royal College of Nursing Research Report, 1998-2004. London, Royal College of Nursing.

Manley K. McCromack B. and Wilson V. (2008) International Practice Development in Nursing and Healthcare. Oxford. Blackwell Publishing Ltd.

Manley K. Titchen A. and McCormack B. (2013) What is Practice Development and What are the Starting Points. In McCormack B. Manley K. and Titchen A. (eds). Practice Development in Nursing and Healthcare. Chichester, Blackwell Publishing.

Manning D. and Dickens C. (2006) Health Literacy: More choice, but do cancer patients have the skills to decide. European Journal of Cancer Care, 15, pp. 448-452.

Mason J. (2012) How many qualitative interviews is enough? In Baker S.E. and Edwards R (eds). University of Southampton, National Centre for Research Methods Review Paper.

May C. Finch T. Mair F. Ballini L. Dowrick C. Eccles M. Gask L. MacFarlane A. Murray E. Rapley T. Rogers A. Treweek S. Wallace P. Anderson G. Burns J. and Heavan B. (2007) Understanding the implementation of complex interventions in health care: the normalization process model. BMC Health Services Research. 7:148. Accessed 12/3/12. www.biomedcentral.com/1472-6963/7/148

Mayer J.D. and Salovey P. (2004) Emotional Intelligence: Key readings on the Mayer and Salovey Model. New York, Dude Publishing.

Mays N. Pope C. and Popay J. (2005) Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. Journal of Health Service Research and Policy. 10 (Suppl. 1), pp. S1:6-S1:20.

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, pp. 428-441.

McCorkle R. Ercolano E. Lazenby M. Schulman-Green D. Schilling L.S. Lorig K. and Wagner E.H. (2011) Self-management: Enabling and Empowering Patients Living with Cancer as a Chronic Illness. Ca Cancer Journal Clin. 61, pp. 50-62.

McCormack B. (2011) Engaged scholarship and research impact: integrating the doing and using of research in practice. Journal of Research in Nursing, 16 (2), pp. 111-127.

McCormack B. and McCance T. (2010) Person-Centred Nursing. Theory and Practice. Chichester, Wiley-Blackwell.

McCormack B. and McCance T. (2006) Development of a framework for person-centred nursing. Journal of Advanced Nursing, 56 (5), pp. 472-479.

McCormack B. and Manley K. (2004) Evaluating Practice Developments. In McCormack B. Manley K. and Garbett R. (eds.) Practice development in Nursing. Oxford, Blackwell Publishing.

McCormack B. Manley K. and Titchen (2013) Practice Development in Nursing and Healthcare. Chichester, Wiley-Blackwell.

McDaniel R.R. Lanham H.J. and Anderson R.A. (2009) Implications of complex adaptive systems theory for the design of research on health care organisations. Health Care Manage Rev, 34 (2), pp. 191-199.

McIlfatrick S. et al (2006a) What about the carers? Exploring the experience of caregivers in a chemotherapy day hospital setting. European Journal of Oncology Nursing, 10, pp. 294-303.

McIlfatrick S. Sullivan K. and McKenna H. (2006b) Nursing the clinic vs. nursing the patient: nurses' experience of a day hospital chemotherapy service. Journal of Clinical Nursing, 15, pp. 1170-1178.

McIlfatrick S. Sullivan K. and McKenna H. (2006c) Exploring the ethical issues of the research interview in the cancer context. European Journal of Oncology Nursing (2006) 10, pp. 39–47.

McKenzie H. Boughton M. Hayes L. Forsyth S. Davies M. Underwood E. and McVey P. (2007) A sense of security for cancer patients at home: the role of the community nurse. Health and Social Care in the Community, 15 (4), pp. 352-359.

McNiff J. and Whitehead J. (2011) All You Need to Know About Action Research. London, Sage.

McQueen A.C.H. (2004) Emotional intelligence in nursing work. Journal of Advanced Nursing, 47 (1), 101-108.

McSherry M. Smith L. and Kell J. (2010) Leadership and Change Management. In McSherry R. and Warr J. (eds.) Implementing Excellence in your Health Organisation: Managing, Leading and Collaborating. Maidenhead, Open University Press.

McTaggart R. (1994) Participatory Action Research: Issues in theory and practice. Educational Action Research, 2 (3), pp. 313-337.

Medical Research Council (2000) A Framework for Development and Evaluation of RCTS for Complex Interventions to Improve Health. London. MRC.

Medical Research Council (2008) Developing and Evaluating Complex Interventions: New Guidance. London. MRC.

Medical Research Council (2014) Process evaluation of complex interventions: UK MRC guidance. London. MRC.

Menzies I.E.P. (1960) A case-study in the functioning of social systems as a defence against anxiety: A report on a study of the nursing service of a general hospital. Human Relations, 13, pp. 95-121.

Menzies Lyth I.E.P. (1988) Containing Anxiety in Institutions. Selected Essays, Volume 1. London, Free Association Books.

Meyer J.E. (1993a) New paradigm research in practice: the trials and tribulations of action research. Journal of Advanced Nursing, 18, pp. 1066-1072.

Meyer J.E. (1993b) Lay participation in care: a challenge for multidisciplinary teamwork. Journal of Inter-professional Care, 7, (1) pp. 57-66.

Meyer J. (1995) Lay participation in care in a hospital setting: An action research study. PhD Thesis, London, King’s College London.

Meyer J. (2006) Action Research. In Gerrish K. and Lacey A. (eds.), The Research Process in Nursing. Chichester, Wiley-Blackwell.

Meyer J. (2010) Action Research. In Gerrish K. and Lacey A. (eds.), The Research Process in Nursing. Chichester, Wiley-Blackwell.

Mezirow J. (1997) Transformative Learning: Theory to Practice. New Directions for Adult and Continuing Education, 74, Summer, pp. 5-12

Michie S. Abraham C. Eccles M.P. Francis J.J. Hardeman W. Johnston M. (2011) Strengthening evaluation and implementation by specifying components of behaviour change interventions: a study protocol. Implementation Science, 6, 10.

Michie S. Fixsen D. Grimshaw J.M. and Eccles M.P. (2009) Specifying and reporting complex behaviour change interventions: the need for a scientific method. Implementation Science, 4, 40.

Michie S. Johnston M. Francis J. Hardeman W. and Eccles M. (2008) From theory to intervention: Mapping theoretically derived behavioural determinants to behaviour change techniques. Applied Psychology, 57 (4), pp. 660-680.

Michie S. Johnston M. Abraham C. Lawton R. Parker D. Walker A., on behalf of the" Psychological Theory Group" (2005) Making psychological theory useful for implementing evidence based practice: a consensus approach. Quality Safe Health Care, 14, pp. 26-33.

Miller S.M. Summerton J. and Brody D.S. (1988) Styles of Coping with Threat: Implications for Health. Journal of Personality and Social Psychology, 54 (1), pp. 142-148.

Miller S.M. (1995) Monitoring versus Blunting Styles of Coping with Cancer Influence the Information Patients Want and Need about Their Disease. Cancer, 76 (2), pp. 167-176.

Mitchell G. (2013) Selecting the best theory to implement planned change. Nursing Management. 20 (1), pp. 32-37.

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

Mohler R. Bartoszek G. Kope S. and Meyer G. (2012) Proposed criteria for reporting the development and evaluation of complex interventions in healthcare (CReDECI): guideline development. International Journal of Nursing Studies, 49, pp. 40-46.

Molassiotis A. Saunders M.P. Valle J. Wilson G. Wardley A. Lorigan P. Levine E. Cowan J. Loncaster J. and Rittenberg C. (2008) A prospective observational study of chemotherapy-related nausea and vomiting in routine practice in a UK cancer centre. Supportive Cancer Care, 16, pp. 201-208.

Moore L. and Savage J. (2002) Participant observation, informed consent and ethical approval. Nurse Researcher, 9 (4), pp. 58-69.

Morris S.M. and 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, pp. 87-95.

Morrow E, Boaz A, Brearley S. and Ross F. (2012) Handbook of Service User Involvement in Nursing and Healthcare Research. Chichester, Wiley-Blackwell.

Mosher C.E. and Danoff-Burg S. (2005) Psychosocial impact of parental cancer in adulthood: A conceptual and empirical review. Clinical Psychology Review, 25, pp. 365-382.

Mulhall A. (2003) In the field: notes on observation in qualitative research. Journal of Advanced Nursing, 41 (3), pp. 306-313.

Munn-Giddings C. McVicar A. and Smith L. (2008) Systematic Review of the uptake and design of action research in published nursing research, 2000-2005. Journal of Research in Nursing, 13, pp. 465-477.

Murchie P. Hannaford P.C. Wyke S. Nicolson M.C. and Campbell N.C. (2007) Designing an integrated follow-up programme for people treated for cutaneous malignant melanoma: a practical application of the MRC framework for the design and evaluation of complex interventions to improve health. Family Practice, 24, pp. 283-292.

Murray E. Treweek S. Pope C. MacFarlane A. Ballini L. Dowrick C. Finch T. Kennedy A. Mair F. O'Donnell C. NioOng B. Rapley T. Rogers A. and May C. (2010) Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. BMC Medicine, 8 (63). Accessed 25/2/11. http://www.biomedicalcentral.com/1741-7051/8/63

National Advisory Group on the Safety of Patients (2013) A promise to learn – a commitment to act. Improving the safety of patients in England. London, Crown Copyright.

National Centre for Social Research (2011) Depth interviewing skills. 21st and 22nd September 2011: Training Course Hand-outs. London, NATCEN.

National Cancer Action Team (2007) Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance. London. King's College London. London, Department of Health, NCAT.

National Cancer Action Team (2009) Chemotherapy Services in England: Ensuring quality and safety. London, Department of Health, NCAT.

National Cancer Action Team (2010) Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist. London, Department of Health, NCAT.

National Cancer Action Team (2011) Holistic Needs Assessment for People with Cancer: A Practical Guide for Healthcare Professionals. London, Department of Health, NCAT.

National Cancer Action Team (2012) Quality in Nursing: A Census of the Chemotherapy Nursing Workforce in England 2012. London, Department of Health, NCAT.

National Cancer Action Team (2013) Connected: Advanced Communication Skills Training. London, Department of Health, NCAT. Accessed 4/12/13.
https://www.connectedonlinebookings.co.uk/about.php

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, NCEPOD.

National Council for Hospice and Specialist Palliative Care Services (2002) Definitions of Supportive Care. Briefing Paper 11, NCHSPCS.

National Health Service (2008) High Quality Care For All – NHS Next Stage Review Final Report. London, The Stationary Office.

National Health Service, England (2011) National Cancer Peer Review Programme Manual of Cancer Services: Chemotherapy Measures Version 1 June 2011. NHS England

National Institute for Clinical Excellence (2004) Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults. London, NICE.

NHMRC (2003) Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer. National Breast Cancer Centre, Camperdown, NSW. National Health and Medical Research Council: website: http://www.nhmrc.gov.au, accessed 5/5/11.

NHS Institute for Innovation and Improvement (2005) Improvement Leaders' Guide: Managing the Human Dimensions of Change. Coventry, University of Warwick Campus.

Nijboer C. Tempelaar R. Sanderman R. Triemstra M. Spruijt R.J. Geertrudis A.M. (1998) Cancer and the caregiving: the impact on the caregiver's health. Psycho-Oncology, 7, pp. 3-13.

Nijboer C. Triemstra M. Tempelaar R. Sanderman R. and Geertrudis A. M. (1999) Determinants of care giving experiences and mental health of partners of cancer patients. Cancer, 86, pp. 577-588.

NICHSR (2011) Glossary, National Information Centre on Health Services Research and Health Care Technology, U.S. National Library of Medicine. Accessed 16/8/11.
http://www.nlm.nih.gov/nichsr/hta101/ta101014.html

Nolan M. (2001) Supporting family carers in the UK: overview of issues and challenges. British Journal of Nursing, 10 (9), pp. 608-613.

Norman I. and Griffiths P. (2014) The rise and rise of the systematic review. International Journal of Nursing Studies, 51, pp. 1-3.

Northouse L.L. (2005) Helping families of patients with cancer. Oncology Nursing Forum, 32 (4), pp.743-750.

Northouse L.L. Katapodi M.C. Song L. Zhang L. and Mood D.W. (2010) Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. Ca Cancer J. Clin. 60, pp. 317-339.

Northouse L.L. Templin T. Mood D. and Oberst M. (1998) Couples' Adjustment to Breast Cancer and Benign Breast Disease: A Longitudinal Analysis. Psycho-Oncology, 7, pp. 37-48.

Northouse L.L. Williams A. Given B. and McCorkle R. (2012) Psychosocial care for family caregivers of patients with cancer. Journal of Clinical Oncology, 30 (11), pp. 1227-1234.

Nursing and Midwifery Council (2008) Code of Professional Conduct, London, NMC.

Ockerby C. Livingston P. O'Connell B. and Gaskin C.J. (2012) The role of informal caregivers during cancer patients' recovery from chemotherapy. Scandinavian Journal of Caring Sciences, 27(1) pp.147-155.

Office of National Statistics (2001) Census 2000/2001 General Household Survey.
http://www.statistics.gov.uk.

Office of National Statistics (2012) Census 2011, General Household Survey. http://www.statistics.gov.uk.

Ogle J.A. and Bushnell J.A. (2014) The appeal of emotional intelligence. Medical Education, 48, pp. 456-465.

Okamoto I. Wright D. and Foster C. et al (2007) The impact of cancer on everyday life. A systematic appraisal of the research evidence. London, Macmillan Cancer Support.

Okumus F. Altinay L. and Roper A. (2007) Gaining access for research. Reflections from experience. Annals of Tourism Research, 34 (1), pp. 7-26.

O'Mara K. (2005) Who's taking care of the caregiver? Journal of Clinical Oncology, 23 (28), pp. 6820-6821.

Orbach S. (1999) Towards Emotional Literacy. London, Virago Press.

Palmieri C. Bird E. and Simcock R. (2013) ABC of Cancer Care. Chichester, BMJ Books, Wiley Blackwell.

Parker G. Corden A. and Heaton J. (2011) Experiences of and influences on continuity of care for service users and carers: synthesis of evidence from a research programme. Health and Social Care in the Community, 19 (6), pp. 576-601.

Pawson R. Greenhalgh T. Harvey G. and Walsh K. (2005) Realist review: A new method of systematic review designed for complex policy interventions. Journal of Health Service Research and Policy, 10, (Suppl. 1), pp. S21-34.

Pepper J.R. Jaggar S.I. Mason M.J. Finney S.J. and Dusmet M. (2012) Schwartz Rounds: reviving compassion in modern healthcare. J.R. Soc. Med. 105, pp. 94-95.

Petticrew A. (2005) The character and significance of management research on the public services. Academy of Management Journal, 48, pp. 973-977.

Petticrew M. and Roberts H. (2006) Systematic Reviews in the Social Sciences: A Practical Guide. Malden, MA, USA, Blackwell Publishing.

Pitceathly C. and Maguire P. (2003) The psychological impact of cancer on patients' partners and other key relatives: A review. European Journal of Cancer, 39, pp. 1517-1524.

Plant H. (1995) The experiences of families of newly diagnosed cancer patients: selected findings. In Richardson A. and Wilson-Barnett (eds.) Nursing Research in Cancer Care. London, Scutari Press.

Plant H. (2008) The impact of cancer on the family. In Corner J. and Bailey C. (Eds.) Cancer Nursing, Care in Context. Oxford, Blackwell Publishing.

Plsek P.E. and Greenhalgh T. (2001) The challenge of complexity in health care. British Medical Journal, 323, pp. 625-628.

Pluye P. Gagnon M.P. Griffiths F. and Johnson-Lafleur J. (2009) A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. International Journal of Nursing Studies. 46, pp. 529-546.

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

Pope C. and Mays N. (2006) Qualitative Research in Health Care. Oxford, BMJ Books, Blackwell Publishing.

Pope C. and Mays N. (1995) Qualitative Research: Reaching the parts other methods cannot reach: an introduction qualitative methods in health and health services research. British Medical Journal. Accessed 25/4/13. www.bmj.com/content/311/6996/42

Pope C. Mays N. and Popay J. (2007) Synthesizing Qualitative and Quantitative Health Evidence: A Guide to Methods. Maidenhead, Open University Press.

Porter R. (2002) Blood and Guts: A Short History of Medicine. London, Penguin Group.

Poses (1999) One size does not fit all: Questions to answer before intervening to change physician behaviour. Joint Commission Journal on Quality Improvement, 25 (9), pp. 486-495.

Potvin L. Bisset S.L. and Walz L. (2010) Participatory Action Research: Theoretical Perspectives on the Challenges of Researching Action. In Bourgeault I. Dingwall R. and De Vries R. (eds.) The Sage Handbook of Qualitative Methods in Health Research. Los Angeles, Sage.

Raelin J. (1999) Preface. Management Learning, 30 (2), pp. 115-125.

Raine R. Sanderson C. Hutchings A. Carter S. Larkin K. Black N (2004) An experimental study of determinants of group judgments in clinical guideline development. Lancet, 364, pp. 429-437.

Ramirez A.J. Westcombe A.M. Burgess C.C. Sutton S. Littlejohns P. and Richards M.A. (1999) Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. The Lancet, 353, pp. 1127- 1131.

Rapaport J. Bellringer S. Pinfold V. and Huxley P. (2006) Carers and confidentiality in mental health care: considering the role of the carer’s assessment: a study of service users’, carers’ and practitioners’ views. Health and Social Care in the Community, 14 (4), pp. 357-365.

Ream E. Richardson A. and Verity R. (2008) Exploring the information and support needs of family members of people having chemotherapy. Research Award. Christine Hewson Memorial Foundation.

Ream E. Pederson V. Richardson A. Taylor C. and Verity R. (2010) Report: Exploring the information and support needs of family members of people having chemotherapy. London, King’s College London.

Ream E. Pedersen V.H. Oakley C. Richardson A. Taylor C. and Verity R. (2013) Informal carers’ experiences and needs when supporting patients through chemotherapy: a mixed method study. European Journal of Cancer Care, 22(6), pp.797-806.

Reason P. (1994) Participation in Human Inquiry. London, Sage.

Reason P. and Bradbury H. (2001) Introduction: Inquiry and Participatory in Search of a World Worthy of Human Aspiration. In Reason P. and Bradbury H. (eds.) Handbook of Action Research: Participative Inquiry and Practice. London, Sage Publications.

Redfern J.M. (2007) Methods for developing and evaluating randomised controlled trials of complex interventions: A case study of stroke secondary prevention. PhD Thesis, Guy's, King's and St. Thomas's School of Medicine. London.

Redfern J. McKevitt C. and Wolfe C.D.A. (2006) Development of complex interventions in stroke care: A systematic review. Stroke, 37, pp. 2410-2419.

Redfern J. Rudd A.D. Wolfe C.D.A. and McKevitt C. (2008) Stop Stroke: Development of an innovative intervention to improve risk factor management after stroke. Patient Education and Counselling, 72, pp. 201-209.

Redsell (2006) New Roles for Nurses and Consultation Skills. In Hastings A. and Redsell S. (eds.) The Good Consultation Guide for Nurses. Abingdon, Radcliffe Publishing.

Reed A. (2011) Nursing in Partnership with Patients and Carers. Exeter, Learning Matters.

Regan T.W. Lambert S.D. Girgis A. Kelly B. Kayser K. and Turner J. (2012) Do couple-based interventions make a difference for couples affected by cancer?: A systematic review. BMC Cancer, 12, p. 279. Accessed 17/9/13. www.biomedcentral.com/1471-2407/12/279

Resendes L.A. and McCorkle R. (2006) Spousal Responses to Prostate Cancer: An Integrative Review. Cancer Investigation, 24, pp. 192-198.

Ritchie J. and Lewis J. (2003) Qualitative research practice: a guide for social science students and researchers. London, Sage, pp. 219-262.

Ritchie J. Spencer L. and O'Connor W. (2003) Carrying out qualitative analysis. In Ritchie J, and Lewis J. (eds.) Qualitative research practice: a guide for social science students and researchers. London, Sage, pp. 219-262.

Robson C. (2011) Real World Research. A resource for users of Social Research Methods in applied settings. Chichester, Wiley.

Rogers C. (1961) On becoming a person. New York, Houghton Mifflin Company.

Rogers E. M. (2003) Diffusion of Innovations. New York, Free Press.

Rolfe G. (1993) Closing the theory-practice gap: A model of nursing praxis. Journal of Clinical Nursing, 2, pp. 173-177. Critical Reflection in Practice: Generating Knowledge for Care

Rolfe G. (2011). Models and Frameworks for Critical Reflection. In Rolfe G. Jasper M. and Freshwater D. (eds.) Critical Reflection in Practice: Generating Knowledge for Care. London, Palgrave Macmillan.

Romito F. Goldzweig G. Cormio C. Hagedoorn M. and Andersen B. (2013) Informal caregiving for cancer patients. Cancer, 119 (11 suppl.) pp. 2160-9.

Royal College of Physicians (2012) Report 'Hospitals on the Edge: Time for Action?' London. RCP.

Russell J. (2013) Action Research, RDS London Newsletter, National Institute for Health Research, Issue 11, Summer 2013.

Rutten L.J.F. Arora N.K. Bakos A.D. Aziz N. and Rowland J. (2005) Information needs and sources of information among cancer patients: A systematic review of research (1980-2003). Patient Education and Counselling, 57, pp. 250-261

Ryecroft-Malone J. (2004) The PARIHS Framework: A framework for guiding the implementation of evidence-based practice. J Nurs Care Qual. 19, (4), pp. 297-304

Ryecroft-Malone J. and Bucknall T. (2010) Models and Frameworks for Implementing Evidence-Based Practice: Linking Evidence to Action. Chichester, Wiley-Blackwell.

Ryecroft-Malone J. Harvey G. Seers K. Kitson A. McCormack B. and Titchen A. (2004a) An exploration of the factors that influence the implementation of evidence into practice. Journal of Clinical Nursing, 13, pp. 913-924.

Ryecroft-Malone J. Kitson A. Harvey G. McCormack B. Seers K. Titchen A. and Estabrooks C. (2002) Ingredients for change, revisiting a conceptual framework. Quality Safe Health Care, 11, pp. 174-180.

Rycroft-Malone J. Seers K. Titchen A. Harvey G. Kitson A. and McCormack B. (2004b) What counts as evidence in evidence-based practice? Journal of Advanced Nursing, 47 (1), pp. 81-90.

Salovey P.and Mayer J.D. (1990) Emotional intelligence. Imagination, Cognition and Personality, 9, pp. 185-211.

Santin O. Coleman H. Mills M. Cardwell CR, Donnelly M. (2012) Psychosocial interventions for informal caregivers of people living with cancer. Cochrane Database of Systematic Reviews 2012, Issue 6. Accessed 21/05/14
http://summaries.cochrane.org/CD009912/psychosocial-interventions-for-informal-caregivers-of-people-living-with-cancer#sthash.6JdmpZ3l.dpuf

Savage J. (2000a) Ethnography and Healthcare. British Medical Journal, 321, (1), pp. 400-2.

Savage J. (2000b) Participative observation: standing in the shoes of others? Qualitative Health Research, 10, pp. 324-339.

Schapira L. (2014) Handling uncertainty. Supportive Cancer Care, 22, pp. 583-584.

Schein E.H. (1996) Kurt Lewin's change theory in the field and in the classroom: Notes toward a model of managed learning. Systems Practice, 9 (1), pp. 27-47.

Schein E.H. (1999) Organisational Culture. American Psychologist, 45 (2) pp. 109-119.

Schein E.H. (2001) Clinical Inquiry/Research. In In Reason P. and Bradbury H. (eds.) Handbook of Action Research: Participative Inquiry and Practice. London, Sage Publications.

Schildmann E.K. and Higginson I.J. (2010) Evaluating psycho-educational interventions for informal carers of patients receiving cancer care or palliative care: Strengths and limitations of different study designs. Palliative Medicine, 25 (4), pp. 345-356.

Schon D.A. (1991) The Reflective Practitioner: How Professionals Think in Action. Aldershot, Hampshire, Arena.

Schoolfield M. and Orduna A. (1994) Understanding staff nurse responses to change: utilisation of a grief-change framework to facilitate innovation. Clinical Nurse Specialist, 8, pp. 57-62.

Schumacher K. L. (1996) Reconceptualising family caregiving: Family based illness care during chemotherapy. Research in Nursing and Health, 19, pp. 261-271.

Shanley C. (2007) Management of change for nurses: lessons from the disciplines. Journal of Nursing Management, 15, pp. 538-546.

Shea B.J. Grimshaw J.M. Wells G.A. Boers M. Andersson N. Hamel C. Porter A.C. Tugwell P. Moher D. and Bouter L.M. (2007) Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Medical Research Methodology, 7 (10). Accessed 16/8/11. www.biomedcentral.com/1471-2288-7-10.

Shiell A. Hawe P. and Gold L. (2008) Complex interventions or complex systems? Implications for Health Economic Evaluation, 336, pp. 1281-1283.

Shippee N.D. Domecq Garces J.P.D. Prutsky Lopez G. Wang Z. Elraiyah T.A. Nabhan M. Brito J.B. Boehmer K. Hasan R. Firwana B. Erwin P.J. Montori V.M. and Murad H. (2013) Patient and service user engagement in research: a systematic review and synthesized framework. Health Expectations, doi: 10.1111/hex.12090.

Silverman J. Kurtz S. and Draper J. (2005) Skills for communicating with patients. Oxford, Radcliffe Publishing.

Simcock R. (2013) Multidisciplinary Care. In Palmieri C. Bird E. and Simcock R. (Eds.) ABC of Cancer Care. Chichester, BMJ Books, Wiley Blackwell.

Skeel R.T. (2007) Handbook of Cancer Chemotherapy. Philadelphia, Lippincott Williams and Wilkins.

Smith P. (1992) The emotional labour of nursing. Basingstoke, Palgrave, Macmillan.

Smith P. (2012) The emotional labour of nursing revisited: Can nurses still care? Basingstoke, Palgrave Macmillan.

Smith P. Pearson P.H. and Ross F. (2009) Emotions at work: what is the link to patient and staff safety? Implications for nurse managers in the NHS. Journal of Nursing Management, 17, pp. 230-237.

Smith V. Devane D. Begley C.M. and Clarke M. (2011) Methodology in conducting a systematic review of systematic reviews of healthcare interventions. BMC Medical Research Methodology, 11:15, accessed 20/11/13. www.biomedcentral.com/1471-2288/11/15

Smollan R.K. and Sayers J.G. (2009) Organisation culture, change and emotions: A qualitative study. Journal of Change Management, 9 (4), pp. 435-457.

Spector P.E. (2005) Introduction: emotional intelligence. Journal of Organisational Behaviour, 16, pp. 409-410.

Speice J. Harkness J. Laneri H. Frankel R. Roter D. Kornblith A.B. Ahiles T. Winer E. Fleishman S. Luber P. Zevon M. McQuellon R. Trief P. Finkel J. Spira J. Greenberg D. Rowland J. and Holland J.C. (2000) Involving family members in cancer care: focus group considerations of patients and oncological providers. Psycho-Oncology, 9, pp. 101-112.

Spencer L. Ritchie J. Lewis J. and Dillon (2003). Quality in qualitative evaluation: A framework for assessing research evidence. Cabinet Office, Crown Copyright.

Spradley J.P. (1980) Participant Observation. Fort Worth, Harcourt Brace Jovanovich College Publishers.

Stalker K. (2003) Carers: An overview of concepts, developments and debates. In Stalker K. (ed.) Reconceptualising work with ‘Carers’. London, Jessica Kingsley Publishers Ltd.

Staniszewska S. Jones N. Newburn M. and Marshall S. (2007) User involvement in the development of a research bid: barriers, enablers and impacts. Health Expectations, 10, pp. 173-183.

Stenberg U, Ruland C.M. and Miaskowski C. (2009) Review of the literature on the effects of caring for a patient with cancer. Psycho-Oncology, 19 (10), pp. 1013-1025.

Stenberg U. Ruland C.M. Olsson M. and Esktedt M. (2012) To live close to a person with cancer: experiences of family caregivers. Social Work in Health, 52 (10), pp. 909-926.

Straus S. Tetroe J. and Graham I.D. (2009) Knowledge Translation in health Care: Moving from Evidence to Practice. Oxford, Wiley-Blackwell.

Stringer (2007) Action Research, 3rd edition. London, Sage Publications.

Sturt J. Whitlock S. and Hearnshaw H. (2006) Complex intervention development for diabetes self-management. Journal of Advanced Nursing, 54 (3), pp. 293-303.

Sullivan C. Longhurst B. Cook A. Bowman E. and Rodell J. (2013) Specialist Nursing Care. In Palmieri C. Bird E. and Simcock R. (eds.) ABC of Cancer Care. Chichester, BMJ Books, Wiley Blackwell.

Surbone A. Baider L. Weitzman T.S. Brames M.J. Rittenberg C.N. and Johnson J. (2009) Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. Supportive Cancer Care, 18, pp. 255-263.

Swanson J.M. McBurneet K. Wigal T. Pfiffner L.J. (1993) Effect of stimulant medication on children with attention deficit disorder: A ‘review of reviews’. Exceptional Children, 6 (2), pp. 154-161.

Swore Fletcher B.A. Dodd M.J. Schumacher K.L. and Miaskowski C. (2008) Symptom experience of family caregivers of patients with cancer. Oncology Nursing Forum, 35 (2), pp. E23-E44.

Tamayo G.J. Broxson A. Munsell M. and Cohen M.Z. (2010) Caring for the caregiver. Oncology Nursing Forum, 37 (1), pp. E50-E57.

Taylor B. (2005) Personal Change. In Hamer S. and Collinson G. (eds.) Achieving Evidence-based Practice. London, Balliere Tindall.

Taylor C. (2008) Supporting the carers of individuals affected by colorectal cancer. British Journal of Nursing, 17 (4), pp. 226-230.

Taylor S. Harley C. Campbell L.J. Bingham L. Podmore E,J. Newsham A.C. Sleby P.J. Selby P.J. Brown J.M. and Velikova G. (2011) Discussion of emotional and social impact of cancer during outpatient oncology consultations. Psycho-Oncology, 20, pp. 242-251.

The Health Foundation (2014) Person-centred care: from ideas to action. London, The Health Foundation.

The King's Fund (2013) Patient-centred leadership: Rediscovering our purpose. London, The King's Fund.

Thomas C. Morris S. Soothill K. McIllmurray M. Francis B. and Harman J. (2001) What are the psychosocial needs of cancer patients and their main carers? Report: The Institute for Health Research, Lancaster University.

Thomas C. Morris S.M. and Harman J.C. (2002) Companions through cancer: the care given by informal carers in cancer contexts. Social Science Medicine, 54, pp. 529-544.

Titchen A. (2003) Critical companionship: part 1. Nursing Standard, 18 (9), pp. 33-40.

Townsend P. (1957). The family life of old people: An inquiry in East London. London, England: Routledge and Kegan Paul.

Turnbull Macdonald G.C. Baldassarre F. Brown P. Hatton-Bauer J. Green E. and Lebel S. (2012) Psychosocial Care for Cancer: A framework to guide practice and actionable recommendations for Ontario. Current Oncology, 19 (4), pp. 209-216.

Turner J. Zapart S. Pedersen K. Rankin N. Luxford K. and Fletcher J. (2005) Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer. Psycho-Oncology, 14, pp. 159-173.

Twigg J. and Atkin K. (1994) Carers Perceived: Policy and Practice in Informal care. Buckingham, Open University Press.

Ussher J.M. Perz J. Hawkins Y. and Brack M. (2009) Evaluating the efficacy of psycho-social interventions for informal carers of cancer patients: A systematic review of the research literature. Health Psychology Review, 3, (1), pp. 85-107.

Van de Ven A.H. (2007) Engaged Scholarship: A Guide for Organizational and Social Research. Oxford. Oxford University Press.

Van de Ven and Johnson P.E. (2006) Knowledge for theory and practice. Academy of Management Review, 31 (4), pp. 802-821.

Van Dyke K.J. McHugh M. Yonek J. Moss D. (2011) Facilitators and barriers to the implementation of patient flow improvement strategies. Quality Management Health Care, 20 (3), pp. 223-233.

Van Meijel B. Gamel C. van Swieten-Duijfjes B. and Grypdonck M.H.F. (2004) The development of evidence-based nursing interventions: methodological considerations. Journal of Advanced Nursing, 48, (1) pp. 84-92.

Van Teijilingen E. Pitchforth E. Bishop C. and Russell E. (2006) Delphi method and nominal group technique in family planning and reproductive health research. Journal of Family Planning and Reproductive Health Care, British Medical Journal, 32 (4), pp. 249-252.

Verity R. (2002) Administering cytotoxic chemotherapy: The nurse's perspective. Unpublished MSc Dissertation. Guildford, University of Surrey.

Verity R. Wiseman T. Ream E. Teasdale E. and Richardson A. (2008) Exploring the work of nurses who administer chemotherapy. European Journal of Oncology, 12, (3) pp. 244-252.

Walker E. and Dewar B.J. (2001) How do we facilitate carers' involvement in decision making? Journal of Advanced Nursing, 34 (3), pp. 329-337.

Waterman H. (1998) Embracing ambiguities and valuing ourselves: Issues of validity in action research. Journal of Advanced Nursing, 28 (1), pp. 101-105.

Waterman H. Tillen D. Dickson R. and de Koning K. (2001) Action Research: A systematic review and guidance for assessment. Health Technology Assessment, 5 (23).

Watson H. Booth J. and Whyte R. (2010) Observation. In Gerrish K. and Lacey A. (eds.), The Research Process in Nursing. Chichester, Wiley-Blackwell.

Wen K.Y. and Gustafoson D.H. (2004) Needs assessment for cancer patients and their families. Health and Quality of Life Outcomes. 2. Accessed 3/11/11. http://hqlo.com/content/2/1/11

Weymes E. (2002) Relationships not leadership sustain successful organisations. Journal of Change Management, 3 (4) pp. 319-331.

Wheelan S.A. (1996) An initial exploration of the relevance of complexity theory to group research and practice. Systems Practice, 9 (1), pp. 49-70.

White S. (2006) Unsettling Reflections: the reflexive practitioner as 'trickster' in inter-professional work. In White S. Fook J. and Gardner F. (eds.) Critical Reflection in Health and Social Care. Maidenhead, Berkshire, Open University Press.

Whitelaw S. Beattie A. Balgoh R. and Watson J. (2003) A Review of the Nature of Action Research. Cardiff, Welsh Assembly Government.

Whitmore R. and Knafl K. (2005) The integrative review: Updated methodology. Journal of Advanced Nursing, 52 (5), pp. 546-553.

Wilding H. (2003) Helping carers: a matter of quality. Practice Development in Health Care, 2 (1), pp. 48-52.

Williamson G.R. Bellman L. and Webster J. (2012) Action Research in Nursing and Healthcare. London, Sage.

Williamson G.R. and Prosser S. (2002) Action Research: politics, ethics and participation. Journal of Advanced Nursing, 40 (4), pp. 587-593.

Wilson K. Pateman B. Beaver K. and Luker K. (2002) Patient' and carer' needs following a cancer-related hospital admission: The importance of referral to the district nursing service. Journal of Advanced Nursing, 38 (3), pp. 245-253.

Wiseman T. Verity R. Ream E. Alderman E. and Richardson A. (2005) Report: 'Exploring the work of nurses who administer chemotherapy: A multi-method study'. London, King's College London.

World Health Organisation (2012) Knowledge Translation Framework for Ageing and Health. McCaster University.

Worthington A. and Rooney P. (2010) Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care. National Mental Health Development Unit. Accessed 10/11/12. http://static.carers.org/files/caretriangle-web-5250.pdf

Worthington A. Rooney P. and Hannan R. (2013) The Triangle of Care. Carers Included: A Guide to Best Practice in Mental Health Care in England. London, Carers Trust.

Wright P. Bingham L. Taylor. Hanif N. Podmore E. and Velikova G. (2012) Managing social difficulties: roles and responsibilities of patients and staff. Psycho-Oncology, 21, pp. 20-28.

Wright S.G. (1998) Changing Nursing Practice (2nd edition). London, Edward Arnold.

Wuest J. (1997) Fraying connections of caring women: An exemplar of including difference in the development of explanatory frameworks. Canadian Journal of Nursing Research, 29 (2), pp. 99-116.

Wuest J. (2000) Re-patterning care: Women's proactive management of family caregiver demands. Health Care for Women International, 21, pp. 393-411.

Wuest J. (2001) Precarious ordering: Toward a formal theory of women's caring. Health Care for Women International, 22, pp. 167-193.

Yin T. Zhou Q. and Bashford C. (2002) Burden on family members: Caring for frail elderly: A meta-analysis of interventions. Nursing Research 51 (3), pp. 199–208.

Appendices

Appendix 1: Data Extraction Form Template

BACKGROUND INFORMATION	
Title :	
Author(s):	*Name, professional background* *Do the reviewers have the appropriate expertise to conduct the review?* *If it is an individual researcher is there a rationale or acknowledgement of the limitations this may create further in the paper?*
Professional background	*What professional background are the reviewers from and has this influenced the approach, conduct or rationale of the review?*
Year:	
Journal:	*Is it a peer reviewed journal?*
Volume:	
Issue:	
Pages:	
Keywords	*Are the keywords relevant and comprehensive?*
Online Access	
Funders	*Potential sources of support and conflict of interests should be clearly acknowledged*
Country	*It is helpful to identify where reviews have been predominately undertaken to appraise whether the findings are relevant, for example, different countries may have different approaches to providing cancer care and chemotherapy services The focus or findings of the review may therefore, not be generalizable to the UK.*

REVIEW DETAILS
TITLE • *Is the title clear and does it provide a reasonable description of the review?* • *Does it identify the paper as a systematic review, meta-analysis etc.?*
Abstract • *If offered is it structured, informative and concise?*
Aim of Review: *Are the aims clearly stated?* *What were the aims?* *Did they arise out of the discussion/background?*
Is there a clearly-focused question?:

Yes:
Question:
No:
Unclear:
The questions should be focused, unambiguous and answerable

RATIONALE FOR UNDERTAKING REVIEW

- *Did the background provide a relevant and appropriate rationale for conducting the review?*
- *What was the rationale?*

Type of Review (Design):

- *Do the authors explicitly state the type of review it is – and do they offer a definition?*
- *Is the method clearly discussed and is it appropriate considering the aims of the review?*

Type of Studies Reviewed:

- *Do the authors explicitly state the type of studies they reviewed? Qualitative, quantitative, RCTS, or mixed methods?*
- *Does the review contain other sources of evidence, e.g. unpublished studies, policies, clinical guidelines?*
- *Were the studies suitable to answer the review questions?*

Definition of carers	• *Have the reviewers defined what they mean by the term carers?* *This has been included to help inform the study by mapping the definitions used for carers in the literature*

Search Strategies

Which Bibliographic Databases were used?

- *Were they comprehensive and appropriate for the research topic/question?*
- *What were they?*

What Search Terms were used?

- *Were they comprehensive and appropriate for the research topic/question?*
- *What were they?*

How did the Reviewers try to identify all relevant studies?

- *All appropriate citation databases were used?*
- *Was there follow up from reference lists?*
- *Was hand searching of relevant journals performed?*
- *Personal contact made with identified experts?*
- *Did the reviewers search for non-English language studies?*

Was there a strategy used to determine which studies were included?

- *Was there more than one reviewer involved?*

Quality Assessment

Were any strategies - tools used/scoring systems etc. to assess the quality of the studies?

- *If so what?*
- *Is quality assessed utilising an appropriate quality assessment criteria which is matched to the methodological design of the reviewed studies?*
- *Was there more than one reviewer involved?*

INCLUSION CRITERIA

- *What was it?*
- *Were they appropriate?*

EXCLUSION CRITERIA

- *What was it?*
- *Were they appropriate?*

RESULTS

Number of studies identified:

- *How many studies were included in the review and is this clearly stated?*

PRESENTATION OF RESULTS

- *How the results are presented – tabular, narratively?*
- *Are they clear and easy to understand?*

RESULTS	
Findings	• *Is there a clear and explicit statement of the findings?* • *What were they?*
Synthesis of findings:	• *The methods used to synthesize the findings been described and defined?* • *Is it an appropriate method?* • *Has more than one method been used?* • *If more than one method has been used has it been sequenced or carried out simultaneously?* • *Has there been an attempt at integration of the different types of findings?*
Characteristics of carers	• *Have these been described in the reviews?* • *If so what are they?*
FOR INTERVENTION REVIEWS	
Classification of interventions	• *How are the interventions classified/defined?*
Contents of interventions	• *Are the components of the interventions described /defined?*
Mode of Delivery	• *How were the interventions delivered?*
Dose	• *How often?*
Who delivered intervention	• *Who delivered the intervention?*

Outcomes measured within studies	• *What outcome measurements were used?*
Intervention outcome measurement time-frames	• *What timeframes were used to measure outcomes?*
Theoretical Frameworks Underpinning interventions	• *What underpinning theoretical concepts/frameworks were used in the intervention studies?* • *Were they reported?*
Fidelity of studies	• *Fidelity refers to the attempts made by the researchers to ensure that the intervention protocol is delivered in a consistent manner.*
KEY DISCUSSION POINTS	
Key Findings	• *What were the general themes in the review?*
Theoretical Concepts	• *Were theoretical concepts/frameworks discussed?* • *If so, what were they?*
Rigour of Review	• *Have the reviewers critiqued the studies in the discussion?* • *Did the reviewers take quality into account when discussing their findings?*
Limitations	• *Have the reviewers outlined the limitations of the review?* • *Are they valid?*
Clinical application of findings	• *Have the reviewers outlined the clinical application of the findings – are they appropriate and feasible?*
Directions for future research	• *Have the reviewers identified gaps in the evidence base?* • *Is this believable in terms of the studies included in the review?*
Main conclusions	
• *What were these and were the overall conclusions consistent with all the evidence from the synthesis?*	

REVIEWER'S COMMENTS:

Theoretical contribution

Does the review offer new insights or theories

Utility of findings for PhD study?

Methodological Rigour

Overall assessment of methodological rigour

Other comments

Any further information that may be useful for the study?

Papers identified that may be useful:

References checked for potential review papers as yet not identified in searches?

Appendix 2: Framework Template

Version Three Framework Analysis Extraction

Questions 1: What are the experiences, roles and needs of informal carers in the chemotherapy treatment setting?

1. Experiences of Informal Carers

1.1 Myriad of emotions
    1.1.1 Feeling overwhelmed
    1.1.2 Worries/Concerns
    1.1.3. Frustration
    1.1.4 Distress and Anxiety
    1.1.5. Dissatisfaction
    1.1.6 Uncertainty and Fear
    1.1.7. Rewards of caregiving
    1.1.8 Feeling Confident
1.2. Impact of Care
1.3 Caregiver Burden
1.4 Fluctuations in experience
1.5 Carers Health
1.6 Impact to Carers Social World
1.7 Relationships between carers and patients
1.8 The Patient is ok – I'm ok
1.9 Gender differences
1.10 Differences age groups
1.11 Spirituality
1.12 Coping strategies informal carers use
1.13 Social support
1.14 Communicating with healthcare professionals
1.15 Receiving support from HPs
1.16 Underutilization of available resources

2. Roles Carers Undertake

2.1 Roles
2.2 Tasks they perform

2.3 Recognition of their roles

2.4 Role Competence

3. Needs

3.1 Treatment related information needs

    3.1.1 How information is used
    3.1.2 Information on treatment services
    3.1.3 Learning needs

3.2 Specific practical/instrumental needs

3.3 Treatment related emotional Needs

3.4 Unmet Needs

3.5 Needs and what families want from healthcare professionals

Question 2: How can healthcare professionals support informal carers in the chemotherapy treatment setting?

4. Helping Carers

4.1 Roles Healthcare professionals Undertake

4.2 Recognising the roles of carers

4.3 Scarcity of interventions and guidelines

4.4 Potentially useful interventions

    4.4.1 Assessment as an intervention
    4.4.2 Interventions for information needs
    4.4.3 Interventions for practical skills
    4.4.4 Interventions for emotional needs
    4.4.5 Interventions for problem solving
    4.4.6 Interventions for enhancing carers perceived confidence
    4.4.7 Interventions providing peer/social support
    4.4.8 The Internet as an Intervention

4.5 Intervention delivery

4.6 Limitations of intervention studies

4.7 Enhancing Interventions

4.8 Working together

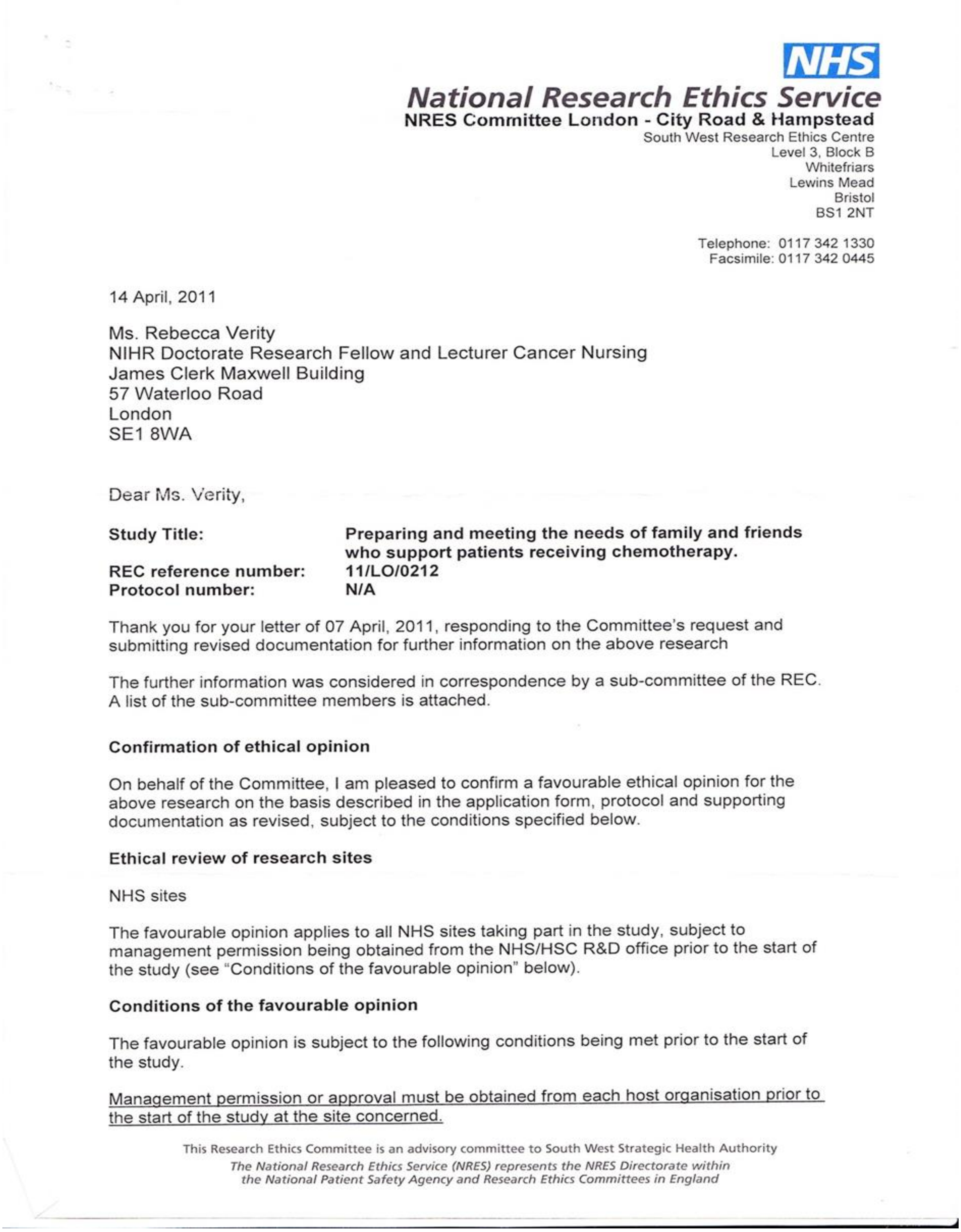
4.9 Challenges/Barriers of supporting carers in the chemotherapy setting

4.10 Understanding cultural influence

Appendix 3: Documents Submitted to Ethics

Outline of Documents Submitted to Ethics Committee	
Step	DOCUMENTATION
Participatory Observation	Invitation letter: Healthcare professionals (all who work in the chemotherapy outpatient setting)
Participatory Observation	Information Sheet: Healthcare professionals (all who work in the chemotherapy outpatient setting)
Participatory Observation	Consent Form: Healthcare professionals(all who work in the chemotherapy outpatient setting)
Participatory Observation	Study Information Letter: to be sent to Patients one week before they attend for appointments
Participatory Observation	Study Poster/Leaflet to be placed around clinical areas one month prior to study starting.
Participatory Observation	Invitation Letter: Patients
Participatory Observation	Patient information sheet
Participatory Observation	Invitation: Informal Carer/Visitors
Participatory Observation	Information Sheet: Informal Carer/Visitors
Participatory Observation	Audit
Interview	Patient Invitation Letter: permission to approach and interview informal carer
Interview	Patient Information Sheet
Interview	Patient Consent Form: To approach informal carer
Interview	Informal Carer Interview Invitation
Interview	Informal Carer Interview Information Sheet
Interview	Informal Carer Consent for Interview
Interview	Informal Carers Contact Details
Interview	Interview: Topics and Exemplar Questions
Interview	Invitation to Healthcare professionals: Interview
Interview	Information Sheet: Healthcare professionals
Interview	Healthcare professionals Consent for Interview
Interview	Interview Topic Guide Healthcare professionals
Interview	Invitation to Informal Carers: Workshops
Workshops	Information Sheet: Informal Carers – Workshops
Workshops	Informal Carer Consent for Workshops
Workshops	Invitation to Healthcare professionals: Workshops
Workshops	Information Sheet: Healthcare professionals: Workshops
Workshops	Healthcare professionals Consent Form: Workshops

Appendix 4: Ethics Approval Letter



National Research Ethics Service
NRES Committee London - City Road & Hampstead
South West Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1330
Facsimile: 0117 342 0445

14 April, 2011

Ms. Rebecca Verity
NIHR Doctorate Research Fellow and Lecturer Cancer Nursing
James Clerk Maxwell Building
57 Waterloo Road
London
SE1 8WA

Dear Ms. Verity,

Study Title: **Preparing and meeting the needs of family and friends who support patients receiving chemotherapy.**
REC reference number: **11/LO/0212**
Protocol number: **N/A**

Thank you for your letter of 07 April, 2011, responding to the Committee's request and submitting revised documentation for further information on the above research

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

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).

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.

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 5: Questions to Help Guide the Observations

	Specific Questions
Who	Who is on duty and working on the unit? Who greets the patient and their visitors when they arrive? Who attends with the patient are they their carers? Who looks after the patients when they are unwell at home? Who does the clinical/holistic assessments? Who do patients/carers talk about in terms of the clinical team? Who engages with carers? Who is responsible for providing the preparation and on-going support to patients and their carers? **Events or specific situations – Who is it about?**
What	What conversations are happening between staff and visitors? (pay attention to the words staff use around patients and their visitors) What conversations are happening between healthcare professionals? What clinical/holistic assessments take place? What information is provided? What events have happened that have caused the patient or carer to contact the unit? What preparation for chemotherapy is required by patients and their carers? What are carers needed for or required to do? What interactions /communications feel difficult? What processes facilitate or impede carers in becoming involved? What support do carers require/receive? What coping strategies do carers use? What support do patients require/receive? What coping strategies do patients use? What support do patients require for carers? What support do healthcare professionals receive? What resources are available for patients, carers and healthcare professionals? What are the possible resource implications to the service if interventions were introduced? What is meant by patient confidentiality in this context? **Events or specific situations – What happened?**
Where	Where is the care delivered (pay attention to Space – layout of the unit, chairs, light, windows, noise) Draw the CDU– take account of atmosphere and general feel of the place How does the unit ‘feel’? Where do patients and their visitors wait and sit within the unit? Where do healthcare professionals position themselves – do they sit with the patient/carer? Where do healthcare professionals interact with carers? Where do clinical/holistic assessments occur? Where are the gaps in the service? **Events or specific situations – Where did it take place?**

	Specific Questions
When	**Time – make a note of time and sequencing of events** When do the patients/carers contact the unit for help or advice? When do carers attend with patients? When do carers approach staff? When do staff approach carers? When do staff contact patients or carers? When do carers ask questions in consultations? **Events or specific situations – When did it take place?**
Why	Why do carers attend with the patient? Why do healthcare professionals interact with carers? **Events or specific situations – Why did it happen?**
How	How is work for the day distributed between staff? How are the appointments planned and structured? How do patients get to their appointments? How are patients and their visitors greeted? How long are patients generally in the unit for? How do healthcare professionals discuss psycho-social issues? How do healthcare professionals assess patients and carers? How do healthcare professionals respond to patient and carer distress, emotions and conflict? How do healthcare professionals address and manage patient and carers concerns? How are pre-chemotherapy consultations organised? **Events or specific situations – How did it happen?**

Appendix 6: Poster for Clinical Areas

With Headed Format & Lager Font.

Research Study: Preparing and meeting the needs of family and friends who support people having chemotherapy

When cancer is diagnosed, it not only affects the person with cancer – it also affects family members and friends. Whilst chemotherapy is mostly given in hospital, much of the job of managing symptoms that can accompany chemotherapy falls to the person with cancer but also in many cases to family and friends.

Starting in June 2011, Rebecca Verity, a nurse researcher from King's College London will be in the department conducting research. The research she will be undertaking aims to develop a package of support which will prepare and meet the needs of family members and friends. To do this Rebecca needs to understand the setting in which care to patients having chemotherapy and their family/friends is given. Rebecca will collect information and data by observing the work undertaken in the chemotherapy outpatient department.

You may be attending appointments while Rebecca is working and collecting data in the chemotherapy outpatient department. If so, you will be invited to take part in the research study and your permission will be sought. If you do attend when Rebecca is here, you will be given full information about the study and a consent form. You will also be given the opportunity to discuss the research with Rebecca. All members of staff working within the department are aware of the study and can also answer your questions.

Please be reassured that all information collected will be entirely confidential. Also it is up to you to decide whether or not to take part. You must feel free to not participate if you wish or withdraw at any time without giving a reason and without repercussions.

THANK YOU FOR READING THIS.

Poster Version 1: 11/2/11
Contact for further information:
Rebecca Verity
NIHR Doctoral Research Fellow/Chief Investigator
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA
Email: rebecca.verity@kcl.ac.uk Direct telephone line: 020 7848 3671

Appendix 7: Carers Interview: Topics and Exemplar Questions

Introduction

- Introduce study
- Clarify the purpose of the interview – emphasise that I want their experience – that everything is valid even the 'little things' in relation to their chemotherapy support and care-giving experience.
- Explain why they were chosen: I wanted a range of people, experiences and situations.
- If on the phone, check this is a good time and explain it is likely to take an hour or so (If bad time, reschedule call)
- Check if they have any questions
- Obtain/ verify consent

Warm-Up

Obtain some background information - explain that I will ask these questions to understand a bit about them and their everyday lives. This will help provide me with some context to the interview.

    - Can you just clarify your relationship to the patient?
    - Working – are they working/would they usually be?
    - Commitments – what would their usual day comprise? Do they have any regular commitments?

Perceptions Of and Feelings about the Chemotherapy Treatment

- Tell me about how you felt when you were first told that N (insert name) was to have chemotherapy:

Carers Perceived Role:

- N has identified you as the person who most supports him/her at home. Tell me what you think that support is?

Perceived Ability to Support Patient through Treatment

- How well equipped did you feel in supporting N through the treatment?

Going To Appointments and Consultations

- Do you go to the chemotherapy outpatient clinic with N?
- Are you welcomed and addressed by your name?
- Are there times when you would like to ask questions but do not wish to do so?
    - If so what stops you?

Navigating the System

- Were you personally offered explanation about the care the patient would receive?
- Did you feel welcomed into the setting?
- You have 'expertise' about the patient that could potentially be helpful to Healthcare professionals – do you think that it is utilised by the HPs.

Experience of Side-Effects

- How involved were you with monitoring or trying to relieve the N problem?

Knowledge and Managing Treatment

- What did you know about the possible side effects of treatment?

- What information and guidance were you given about other aspects of supporting someone through chemotherapy?

Contacting the healthcare team
- Was there ever a time when you thought about contacting the hospital team for advice or support? Who could you contact if you had any concerns when you were at home?

Impact on Carer

Tell me how supporting someone having chemotherapy has impacted on YOU personally:
- Appreciate that this can be overwhelming for you tell me:
    - Your health
    - Your emotions/feelings
    - Your relationships (family/ friends)
    - Your work (if working)
    - Other commitments
    - Finances

Impact on relationship with the one you are caring for
- Do you feel that your relationship with the person you are caring for has changed?
- Communication between the two – do you share your concerns with that person?
    - If communication is a problem, could HPs help you to be more open with each other?

Explore Support Provided by Hospital Healthcare Team
- Who in the team could you turn to for support or advice for your needs?

Other Sources of Support
- Who else have you turned to for help to support you in caring for the N?
    - Other healthcare professionals not attached to the chemotherapy outpatient setting.
    - Charities e.g. Macmillan
    - Friends/family
    - Others in a similar situation
- What would you recommend to someone who was going through what you have been through?

Final Questions about Enhancing Service
- Is there anything you can think of that the doctors and nurses could do differently to make the experience of supporting someone through chemotherapy easier?
- Is there anything that might help you manage better at home?

Close Interview
- Is there anything else you might want to add?
- Check with participant that they know and remember what will happen to the data

Thank the participant

Appendix 8: Patient Invitation – Request to Approach Carer

On headed paper

Date:

Dear Sir/Madam,

Research Study: Preparing and meeting the needs of family and friends who support people having chemotherapy.

I would like to invite you to take part in a research study. The study is trying to understand better the experiences of people supporting those having chemotherapy and the help they may need. I refer to such friends and relatives as informal carers.

When cancer is diagnosed, it not only affects the person with cancer – it also affects family members and friends. Whilst chemotherapy is mostly given in hospital, much of the job of managing symptoms that can accompany chemotherapy falls to the person with cancer but also in many cases to family and friends. I am aware that supporting someone while they are having chemotherapy may raise issues for those people that are different to the needs of the person with cancer – I wish to find out more about their needs.

This study aims to develop a package of support (I refer to this here as an intervention) which will prepare and meet the needs of family members and friends (I refer to these people here as informal carers). In order to do this I need to gain an understanding of the experiences of informal carers supporting someone through chemotherapy treatments. I also want to identify what support informal carers feel they need from the service and healthcare professionals while supporting someone having chemotherapy.

To do this, I need to firstly obtain some information from you (see attached) about you and your treatment. The information you provide will be treated as **STRICTLY CONFIDENTIAL.** While you do not have to answer these questions, the information you provide, will help me to ensure that the people I invite for interview will represent a wide range of people and situations.

I will then require permission from you to contact someone who you feel supports you most through your treatment. I have also enclosed a study pack, including a study invitation, information and a written consent form for the person you nominate.

The interview with the person you identify will take between 60-90 minutes and will be held in a venue that is convenient for that person. Before you decide whether you wish to participate or not, please read the study information sheet. Please also feel free to discuss this study with the person you feel supports you most through treatment before you decide.

Please be aware that any information you give me will be treated in confidence and will not be shared with any of the healthcare professionals involved in your care. If, after you have read the information sheet and are satisfied any queries have been answered, you and your nominated person decide to participate, please can you both read and sign all the forms giving your consent to participate in the research, keep one copy of each form for yourself and place one copy in the envelope and give it to me in the chemotherapy outpatient department or return it by post. I have also enclosed a stamped addressed envelope for you to return the consent form to me.

If you have any questions about this study, please do not hesitate to contact me.

Thank you for considering participating in this study.
Yours faithfully,

Rebecca Verity
NIHR Doctoral Research Fellow/Chief Investigator
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA
Email: rebecca.verity@kcl.ac.uk Direct telephone line: 020 7848 3671
Mobile: 07792677280

Appendix 9: Patient Information Sheet for Permission to Approach and Interview Carer

Research Study: Preparing and meeting the needs of family and friends who support people having chemotherapy.

I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the study is being done and what it would involve for you. Please take time to read the following information carefully and decide whether or not you wish to take part. Ask me if there is anything that is not clear or you would like more information about.

Thank you for reading this.

What is the purpose of this study?

When cancer is diagnosed, it not only affects the person with cancer – it also affects family members and friends. Whilst chemotherapy is mostly given in hospital, much of the job of managing symptoms that can accompany chemotherapy falls to the person with cancer but also in many cases to family and friends.

This study aims to develop a package of support (I refer to this here as an intervention) which will prepare and meet the needs of family members and friends (I refer to these people here as informal carers). In order to do this I need to gain an understanding of the experiences of informal carers supporting someone through chemotherapy treatments. I also want to identify what support informal carers feel they need from the service and healthcare professionals.

Why have I been chosen?

You have been chosen because you are having chemotherapy treatment in an outpatient clinical setting. This means that you may have side-effects and symptoms that accompany chemotherapy which you need to manage at home.

Do I have to take part?

It is up to you to decide whether or not to take part. Please take time to read this information sheet. You are free to withdraw at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care received by you.

What will happen to me if I take part?

There are three things you need to agree too if you and your informal carer take part. Firstly I need to obtain some information from you regarding you and your treatment. The information you provide will be treated as **STRICTLY CONFIDENTIAL.** While you do not have to answer the questions, the information you provide, will help me to ensure that the people I invite for interview will represent a wide range of people and situations.

I also require permission from you to approach someone who you feel supports you most through your treatment. I will be giving you a study pack for you to give to that person this will contain an invitation, information about the study and a consent form.

The following may help you decide who you should nominate as your informal carer, that is, the person you feel supports you most through chemotherapy treatment:

- This person is the person who comes immediately to mind as most involved in supporting you through chemotherapy treatment. This person is often a husband, wife, or partner but sometimes a relative or friend.
- This person can be a man or woman of any age, who may or may not live with you.
- This person may not necessarily do physical tasks for you, such as cooking or cleaning but they may provide for example, company and emotional support.
- This person is NOT someone who is paid to look after you (e.g. a nurse or home help).

If you do allow me to approach your informal carer to take part in this research, I would also like your permission for me to access your medical record so we can collect information on treatment you have received. This information will be kept strictly confidential.

What will happen to my family member/friend?

The person you identify as someone who supports you most while having chemotherapy will be asked to share their experiences in an interview. It will be up to your nominated person to decide whether or not they wish to take part. The interview is also about the information and support they have received and will help me identify what is most and least helpful and ensure chemotherapy services are able to provide better care and support in the future. If they agree, I would like to tape record the interview as I do not want to miss anything they say. Taking notes would mean I could not always concentrate on what they were saying.

What other information will be collected in the study?

For this study data has been collected through participatory observation in the chemotherapy outpatient setting. In addition to collecting data through observation, I will be interviewing healthcare professionals who have experience of caring for people having chemotherapy and their families. I also plan to interview approximately twenty-five informal carers who support patients who are having chemotherapy as an outpatient. Once data has been collected through participatory observation and interview, I plan to hold a series of workshops. Informal carers and healthcare professionals will be invited. The aim of these workshops will be to feedback findings from previous stages of the research and to identify ideas for interventions (package of support) that could be used for informal carers in the chemotherapy setting.

What are the possible disadvantages of taking part?

The interview with your family member/friend will take between 45-60 minutes and will be held in a venue that is convenient for them. The questions should not be upsetting, but might raise issues of concern. If they would like to discuss any issues or feelings raised by taking part in the interview in the first instance you could talk to me, Rebecca Verity and I will do my best to address their concerns, or they could talk to the relevant Clinical Nurse Specialist who is involved in your care.

What are the possible benefits of taking part?

The findings of this study will provide information on how best to support informal carers while their relative/friend is having chemotherapy. Although this may not benefit you personally, information you and the person who support you give may help influence and shape services in the future.

What information will be held about me?

I will follow best ethical and legal practice and all information about you will be handled in confidence. The data collected for the study will be analysed to learn more about the needs of informal carers and how to meet these needs.

Any information your family member/friend shares with me in the interviews will be heard only by me and a research assistant who will be transcribing the recordings of the interviews. However they will be unable to identify them and only I will know the names of the people being interviewed. The tapes of the interview will be destroyed once they have been transcribed and analysed. The tapes and transcripts will be numbered and will not show your name. You and your informal carer's anonymity will be maintained in the final report.

I, as the Chief Investigator, will be responsible for security and access to the data. At the end of the study data will be secured for seven years in keeping with standard research practice.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you or your informal carer might suffer will be addressed.

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your question. If you remain unhappy and wish to complain formally, you can use the normal National Health Service complaints mechanisms and contact the complaints department within the South London Healthcare Trust. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against King's College London but you may have to pay your legal costs.

What will happen to the results of the research study?

This research will be written up for submission of a PhD Thesis. The funding body that supported this research also require a report. The results will also be published in professional journals and presented at conferences. They will be shared with staff involved in providing chemotherapy services to help plan future services. If you would like a copy of the findings I will be happy to send you these.

The findings will ultimately be used to improve the range and nature of support services on offer to informal carers. However, the study will take three years in all, so please do not expect any immediate changes in services.

Who is organising and funding the research?

The research is organised by me (Rebecca Verity) and I am being supported by two academic supervisors from King's College London, Professor Emma Ream and Professor Sarah Cowley.

A project advisory group comprising key stakeholders including the Lead Cancer Nurse, Chemotherapy Lead Nurse, a General Practitioner, an Oncology Consultant, the local Cancer Network User Partnership Facilitator, and patient and informal carer representatives, has also been established. This group will provide me, as the researcher, the opportunity to seek guidance on the conduct and methods of the research and development phases, and review progress and feedback findings. This group will have input at regular intervals throughout the study.

This study has been funded by a Doctorate Research Fellowship Award from the National Institute of Health Research (NIHR).

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given a favourable opinion by the East Central London REC 1 committee (11/LO/0212).

Contacts for further information

NIHR Doctoral Research Fellow/Chief Investigator
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA
Email: rebecca.verity@kcl.ac.uk Direct telephone line: 020 7848 3671
Mobile: 07792677280

Version 1
11/2/11

Appendix 10 Patient Consent to approach Carer

Study Number:
Patient Identification Number for this study:

CONSENT FORM

Title of Project: Preparing and meeting the needs of family and friends who support people having chemotherapy.

Name of Researcher: Rebecca Verity

Please initial box

☐ I confirm that I have read and understand the information sheet dated (11/2/11)(version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that if for any reason I decide not or I am unable to continue in the study any information that I have already given previously will be retained.

☐ I give permission for the Rebecca Verity to contact my relative/friend.

☐ I agree for information to be recorded from my medical notes.

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

When completed, 1 for research subject; 1 for researcher site file notes
Version 2
25/3/11

Appendix 11: Patient Screening questions

The information provided will be treated as **STRICTLY CONFIDENTIAL.** While you do not have to answer these questions, the information you provide will help me to ensure that the people invited for interview will represent a wide range of people and situations.

Section		***Please tick one box per section***
Are you?	Male	
	Female	
Is this your first course of chemotherapy?	Yes	
	No	
What is your age group?	18- 21	
	22-29	
	30-39	
	40-49	
	50-59	
	60-69	
	Over 69	
What is your ethnic group?	White	
	Mixed	
	Asian/ Asian British	
	Black/ Black British	
	Other Ethnic group If other please describe	
How would you describe the relationship with the person who supports you most while having chemotherapy?	Parent	
	Spouse/Partner	
	Sibling	
	Daughter/Son	
	Friend	
	Other If other please describe relationship	
Do you live in the same house with the person who supports you most while having chemotherapy?	Yes	
	No	
	Intravenously	

Section		***Please tick one box per section***
How is your chemotherapy administered?	Orally	
	Both Oral and Intravenous	
While having chemotherapy has there ever been a time when you needed to contact the hospital team for emergency help/ support?	Yes	
	No	
While having chemotherapy have you had any of the following side-effects which have been severe enough to seek emergency help from the hospital team?	Infection	
	Vomiting	
	Diarrhea	
	Other If other please describe the side-effect/s	

Version 2

25/3/11

Appendix 12: Patients Interview Topic Guide

Introduction

- Introduce study
- Clarify the purpose of the interview – emphasise that I want their experience – that everything is valid even the 'little things' in relation to their views on their informal carers role with helping them through chemotherapy.
- Explain why they were chosen: I wanted a range of people, experiences and situations.
- If on the phone, check this is a good time and explain it is likely to take an hour or so (If bad time, reschedule call)
- Check if they have any questions
- Obtain/ verify consent

Warm-Up

Obtain some back ground information - explain that I will ask these questions to understand a bit about them and their everyday lives. This will help provide me with some context to the interview.

- Can you tell me a little about yourself
    - Working, Family, other commitments?
    - When they were diagnosed
    - Where they are in the treatment phase

Perceptions Of and Feelings about the Chemotherapy Treatment

- Tell me about how you felt when you were first told that you were going to have chemotherapy

- What were your main concerns at this time?

Carers Role:

- Can you just clarify your relationship to the carer?
- You identified (name) as the person who most supports him/her at home. Tell me what you think that support is?
- You felt it was important that I interview your carer can you tell why that was?
- What are the main things do they do to support you?
- How important are they to you in this process?

Going To Appointments and Consultations

- Were you asked to bring someone with you to your appointments
- Do you find it useful to take someone with you?
- What role does this person play when they attend appointments
- Did they go to the chemotherapy outpatient clinic with you?
    - If yes when do they attend?
- Are there times when you wanted them to attend appointments and they couldn't?
    - If so, what prevented them from attending?
- Does the HP involved in your care communicate with your family/friends who support you
    - If yes/no how does this make you feel,
    - If yes is it helpful

- Has there ever been a time when you felt that the person supporting you was involved too much with HPs – can you give me an example?

Navigating the System

- How easy have you found it to understand the treatments you were having?
- Did you have information regarding the organisation of care?
- Was (name) offered any information from the service?

Experience of Side-Effects

- How affected were you by side effects?
- How did you try to do to manage the problem?
- How involved was (name) with monitoring or trying to relieve the problem?

Impact on Carer

How has the experience of having chemotherapy impacted on (Name) personally?

Explore Support Provided by Hospital Healthcare Team

- How close have you felt to the Healthcare team in the hospital?
- Who in the team could you turn to for support or advice for your needs?
- Do you think there is anyone in the service that Name could turn to for advice or support?
- Was there anything that you feel you would have liked more help with?
- Was there anything that you feel (Informal Care: Name) could have had more help with?
- Reflecting on the information and support given to you by the chemotherapy services team
  - What did you find most and least useful?
  - What would you have appreciated more support and information on?
- Has there been a time when (Carer) has contacted the team at the hospital – if yes why?

Final Questions about Enhancing Service

- Is there anything you can think of that the doctors and nurses could do differently to help (family/friend name) support you through chemotherapy?
- Is there anything that might help them manage better at home?
- What kind of support would be helpful?
- Who should deliver it?
- What would you recommend to someone who was going through what you have been through? (added August 8, 2012)
- In what ways could family members communicate more effectively with HPs? (added August 13, 2012).

Close Interview

- Is there anything else you might want to add?
- Check with participant that they know and remember what will happen to the data
- Thank the participant

Appendix 13: Healthcare professionals Interview Topic Guide

Introduction

- Introduce study
- Clarify the purpose of the interview – emphasise that I want their perceptions and experience – that everything is valid even the 'little things' in relation to their professional role of supporting carers.
- Explain why they were chosen
- If on the phone, check this is a good time and explain it is likely to take an hour or so (If bad time, reschedule call)
- Check if they have any questions
- Obtain/ verify consent

Warm-Up

Obtain some background information

- Ask them about their role
    - Do you enjoy your work/role
    - What brings you satisfaction about your job
- How much contact do they have with carers

Healthcare professionals Understanding of the Carers Role and Their Needs

- Tell me who you think the carer is?
- How do you think these people support patients through chemotherapy?
- How involved do you think carers should be in the patients care received from healthcare professionals?
- What do you think their needs are?

The Support Given to Carers in the Clinical Setting and Primary Care

- Tell me how the service supports carers?
- Tell me what you do to prepare and support carers to support patients having chemotherapy?
- Who is responsible for supporting ICs – whose role is it
- What are their expectations for those roles

The Perceived Barriers of Providing Carers Support

- **Do you have any difficulties in supporting carers?**
    - If yes – what?
    - If no – why?
- What are the barriers? Communication skills

Training

- Have you had specific training – would you value more?

Improving the Support Given to Carers

- Do you think the support given by the service to carers should be improved?
- If yes how and if no why not?
- Is there anything that would help you improve the support you give to carers?
    - If yes – what?
    - If no – why?
- In an ideal world where there were no constraints how should ICs be involved in the acute cancer setting?

Close Interview

Is there anything else you might want to add

- Check with participant that they know and remember what will happen to the data
- Thank the participant.

Appendix 14: Key Themes from Participatory Observation

The Chemo Factory

- ‘It’s relentless’
    - No time to think
- We have a job to do
- ‘Our priority is to get the drugs in safely’
- ‘Spinning plates’
- No privacy
- No space
- ‘The tale of two chairs’
- Adverse events - reactions
- The important role of the support workers
    - Creating a welcoming environment

Patients and their Visitors/Companions

- The importance of ‘WE’ (patients and families)
    - They’re ok, I’m ok’
- ‘They are lovely here’
- Jokes and humour
    - The Importance of Being Happy: carers and patients need HPs to be upbeat.
- So accommodating,
- ‘They all know you’
- The worst thing is the uncertainty
- Patients protecting their loved ones
- ‘It affects her more than me’ (patients)
    - ‘she needs to talk to someone about this’
- The carers complain – waiting times, etc.
- Overwhelming info and is very frightening
- The information paradox - ‘do not know what to expect”

Patients

- Want some peace
- Boring for them
- Independence – my disease, my problem, my treatment.
- Do not want to be a burden
- Want to carry on as normal
- ‘I (patient) do not want to know really’
- Won’t seek help or delay
- Patients get irritable with relatives
    - ‘do not fuss’

Interactions between CDU staff and patients

- They know the patients
- The importance of keeping happy
- The patients care about the staff
    - Chocolates
- They have favourites
- The patients know the staff
    - Nurses talk about themselves

Key Roles ICs seem to take.

- ‘A pair of ears’
- To be there – emotional support
- To see what is going on
- Complain
- Telephone callers
- Seek information
- Provide food
- Conversationalists
- Companions
- Write notes

Interactions between HPs and ICs

- HPs rarely acknowledge patients’ visitors
    - Do not ask to be introduced
- When there is a crisis
- Difficult carers

Interactions between Patients and Carers

- Tensions
- Blocking
- Supportive
- Silent
- Need to be jolly

The Healthcare professionals’ World

- Staff focused on politics and merger of the organisation
- Constant change – no change
- Patients and carers unaware of the politics
- Patients and Carers get confused about how the system works
- Resistance to change
- Resigned, acceptance, helplessness
- Stuck in mud
- Support each other
- Being managed

The Problems of Busy-ness

- They are very busy here
- Why don’t they (patients) ring? - “they think you are too busy”
- “Just skim the surface”
- Reactive to needs rather than proactive
- Time not used effectively
- Do too much of the unnecessary
- Staff can’t see what they are doing

Working together

- Difficulties with engaging with medics and medics engaging
- Medics do not understand carers’ roles
- Do not understand each other’s roles
- ‘Friends can be good medicine’ (CNS)
    - Supporting each other.
    - Humour
    - Gossip
- No handovers or sharing of information

The Parameters of Working with Carers

- Everyone is different
- Trained to focus on the patient
- Only got time for the patient
- Mission Statement
- No agreed objectives – or guidelines:
    - HPs and organisation not able to evaluate the involvement of carers
- Conflict of care – confidentiality
    - Patient-centred care and the therapeutic relationship
    - Where do they (HPs) draw the line?
- Therapeutic relationships built on trust and respect
    - Should we expect the patient’s health professional to build a therapeutic relationship with carers?

Medical Consultations

- Just ten minutes
- Visitors not acknowledged
- Focused on disease or treatment
- The important role of the CNS
- Difficult conversations

Pre-chemotherapy Consultations

- Behind closed doors
- Ticking boxes – medical information
- All about the health professional’s agenda
- No assessment – knowledge or needs

- So much information
- The information paradox
- Everyone is different
- Structures and format
- It is all more bad news

Assessment

- Medically focused
    - Toxicities
- Ad-hoc
- Not documented
- Tools
    - It’s a tick box exercise

Interpersonal Skills

- I can’t say I do not know
- Everyone is different and one size does not fit all
- We need more tools for our toolbox
- “Opening a can of worms”
- Ticking boxes
- Managing the emotions in the room
    - Blocking
    - Information
- Some do it really well
    - Actively listen
    - Respond to cues
    - Ask about concerns
    - Acknowledge the difficulty

MDTs

- Focused on disease and treatment
- Surgeons showing off
- Conflict
- CNS rarely speak in meetings
- CNS views not sought
- The diplomat CNS: managing the different styles and skills of the team
- CNSs – ‘smooth the way’
    - CNS the administrator

Appendix 15: Carers Analytical Framework

1.0 Context-Background FACTS only

- 1.01 Employment
- 1.02 Commitments e.g. looking after children or parents
- 1.03 Carers Health
- 1.04 Previous Cancer Experience
- 1.05 Social Support (family & friends)
- 1.06 Illness trajectory
    - 1.06.01 Pre-diagnosis Trajectory
    - 1.06.02 how long since patient was diagnosed?
    - 1.06.03 Treatment effectiveness
    - 1.06.04 Treatment trajectory

2.0 Impact of diagnosis

- 2.01 How it felt when patient was diagnosed

3.0 Perceptions of Chemotherapy (Initially)

- 3.01 Pre-conceived ideas
- 3.02 Side-effect worries or fears before chemo

4.0 Experience of treatment (actual)
- 4.01 Reality different from preconceptions
- 4.02 Adverse Reactions
- 4.03 Stayed with patient in CDU
- 4.04 The environment
- 4.05 Experience of side-effects
- 4.06 It's a Long Haul
- 4.07 Got confused about treatment trajectory
- 4.08 Led by the patient

5.0 Preparation for treatment
- 5.01 Did they feel prepared?
- 5.02 Information received
- 5.03 Information overload
- 5.04 Other information received (not about treatment)
- 5.05 Pace of diagnosis or treatment
- 5.06 Unclear of treatment intent
- 5.07 Sought out other information
    - 5.07.01 Information from internet
    - 5.07.02 Information from friends who have experienced treatment
    - 5.07.03 Information from Macmillan or other voluntary organisations
    - 5.07.04 Information from colleagues
    - 5.07.05 Information from HPs not associated with treatment centre
- 5.08 Didn’t seek information

6.0 Carer Roles

- 6.01 A 'pair of ears'
- 6.02 24-7 Support
- 6.03 Record or diary keeper
- 6.04 Side-effects & Symptom controller (monitoring and managing)
- 6.05 Link between hospital & home
- 6.06 Seeker of advice
- 6.07 Information gatherer
- 6.08 Information processor
- 6.09 Protector
- 6.10 Encourager
- 6.11 Normality keeper
- 6.12 Provider of emotional support
- 6.13 Manager of medicines and injections
- 6.14 Manages finances
- 6.15 Provider of practical support
- 6.16 Do whatever you can
- 6.17 Being assertive
- 6.18 Advocate
- 6.19 Complainer
- 6.20 Plans ahead
- 6.21 Manages diet
- 6.22 Nurse
- 6.23 Share the roles

7.0 Experiences with the Service-healthcare professionals

- 7.01 Their perceptions of the service
- 7.02 Having to navigate the system
- 7.03 Perceptions of Busyness
- 7.04 Service and-or Staff are for the patient
- 7.05 Were they offered support for their needs?
- 7.06 Who do they talk about on the team?
- 7.07 Chemotherapy Nurses
- 7.08 Site specific nurses (CNS)
- 7.09 Medics
- 7.10 Emergency Acute Care on Call
- 7.11 A&E
- 7.12 G.P. Care
- 7.13 Ambulance Drivers
- 7.14 Support Staff
- 7.15 The wig lady
- 7.16 Didn’t want to talk to HPs
- 7.17 Do not go to appointments
- 7.18 Needed to talk to someone without the patient knowing
- 7.19 Problems with care or service
- 7.20 HPs not aware of carers needs
- 7.21 Didn’t know who the CNS was
- 7.22 Counselling
- 7.23 Staff showed me how to do it

- 7.24 Chemo nurses refer to CNS
- 7.25 You need to be assertive
- 7.26 Assessment on the chemo unit

8.0 Contacting the service

- 8.01 Didn't know who to contact
- 8.02 When do they contact for advice
- 8.03 Did they feel able to seek advice?
- 8.04 What advice were they given?

9.0 Aspects of supportive care

- 9.01 Importance of HPs being happy
- 9.02 What support means to them
- 9.03 Feeling safe
- 9.04 Being Normal
- 9.05 They're welcoming
- 9.06 Being included 'it really is a WE'
- 9.07 Need to trust the HPs
- 9.08 Staff gets the balance right
- 9.09 Problems with communication between services
- 9.10 The NHS is there to support the patients
- 9.11 Empathy
- 9.12 Recognising the IC as a resource
- 9.13 Previous experiences of the NHS
- 9.14 They build up a relationship
- 9.15 HPs make eye contact
- 9.16 Staff are professional – or they act

10.0 Experience of Consultations
- 10.01 Importance of being at the consultations
- 10.02 Their role in consultations
  - 10.02.01 Writing things down
  - 10.02.02 Help with the bad news
  - 10.02.03 Hear things that the patient won't
  - 10.02.04 Do they ask about you
  - 10.02.05 Would not have wanted to talk to HPs
  - 10.02.06 Patient blocks carers' involvement
  - 10.02.07 Asks questions the patient forgets
  - 10.02.08 Did the health professional include the carer?

- 10.03 Pre-chemotherapy Consultation (information)
- 10.04 Drs won't tell you everything
- 10.05 Do not go to the consultations

11.0 Their Experiences of being a carer
- 11.01 Being called a carer
- 11.02 Feel frightened

- 11.03 Feel frustrated
- 11.04 Feel responsible
- 11.05 Feel alone
- 11.06 Helpless
- 11.07 Feel guilty
- 11.08 Want to be normal
- 11.09 Want to be alone sometimes
- 11.10 You have to get on with it
- 11.11 Living in each other’s pockets
- 11.12 'We're in it together'
- 11.13 Bystander-'one-step away' from the experience
- 11.14 Uncertainty
- 11.15 Impact on Roles
- 11.16 Impact on holidays
- 11.17 Impact on life
- 11.18 Impact on health
- 11.19 Impact on work
- 11.20 Exhausting
- 11.21 Got to be the strong one
- 11.22 Makes you think about mortality
- 11.23 Feel resentful
- 11.24 Feel trapped
- 11.25 I want to do this it’s what you do
- 11.26 I had to grow up

12.0 Relationship with patient

- 12.01 Communication
- 12.02 Protect each other
- 12.03 Patient protects the carer

13.0 Challenges for carers

- 13.01 Language barriers
- 13.02 Not understanding medical knowledge
- 13.03 Managing the patient's emotions
- 13.04 Managing their own emotions
- 13.05 Seeing the patient being unwell
- 13.06 Learning to give injections
- 13.07 Uncertainty about prognosis
- 13.08 Patients want-need to be independent
- 13.09 Patients are not always truthful
- 13.10 Patients do not want to ask
- 13.11 They do not want to know too much
- 13.12 Patients do not want people to know
- 13.13 Find it difficult to talk to people about it
- 13.14 Managing co-morbidities
- 13.15 Food & managing diets
- 13.16 Do not know what to say or do
- 13.17 Managing other family members reactions
- 13.18 Everyone is different
- 13.19 Patient losing their hair

- 13.20 Managing other commitments
- 13.21 When patients refuse to do what they are meant too.
- 13.22 Managing other commitments
- 13.23 Dread the weekends
- 13.24 Patients have little insight into the impact on carers
- 13.25 Carers Allowance
- 13.26 HPs and patients assume you will be a carer
- 13.27 Won’t expect anyone to do this for me
- 13.28 The hardest bit
- 13.29 Patients do not remember
- 13.30 Patients get self-absorbed
- 13.31 Patients are vulnerable
- 13.32 It must be awful for people if they got someone
- 13.33 Geographical distance
- 13.34 Older than patient
- 13.35 Uncertainty about the worth of treatment
- 13.36 Finances

14.0 Problems with service

- 14.01 Car Parking
- 14.02 Waiting times
- 14.03 The wig lady
- 14.04 Communication between services
- 14.05 Do not want to complain
- 14.06 Getting the right advice at the right time e.g. finances
- 14.07 Staff who are not experienced or not aware e.g. A&E
- 14.08 The environment
- 14.09 Documentation and sharing info about the patient
- 14.10 Chemotherapy nurses are not as knowledgeable as the CNS
- 14.11 Staff shows their emotions
- 14.12 Misdiagnosis
- 14.13 Communication between HPS
- 14.14 Left to get on with it.
- 14.15 The Cuts
- 14.16 Weekends and bank-holidays
- 14.17 Care
- 14.18 Continuity and co-ordination of care
- 14.19 No aftercare

15.0 What has helped?

- 15.01 Support from family
- 15.02 Support from friends
- 15.03 Support from work or colleagues
- 15.04 Faith or religion
- 15.05 Trying things out
- 15.06 Humour
- 15.07 Staying in the present
- 15.08 Not knowing too much

15.09 If the patient is ok - I'm ok
15.10 Having a sense of continuity
15.11 Time and experience
15.12 Cancer is not their whole life
15.13 Continuity of care
15.14 Build up a bank of questions
15.15 Being informed
15.16 Focus on one thing at a time
15.17 Staff manages confidentiality issues
15.18 Not talking about cancer or the future
15.19 It’s taught me things
15.20 Peer support

16.0 What would help?

16.01 Having their role acknowledged
16.02 Having information for them personally
16.03 Being encouraged in their role
16.04 Time
16.05 To know who to contact
16.06 Staff proactively contacting patient
16.07 They really had to think about it
16.08 Better prepared
16.09 Do not want anything from the NHS
16.10 Writing things down
16.11 A one to one by themselves
16.12 An opportunity to just talk
16.13 Bereavement counsellor
16.14 More help at home
16.15 Ensuring that there is continuity of care and info
16.16 More CNS
16.17 Having a reliable and compassionate source of help
16.18 Support groups
16.19 Someone escort the patient
16.20 follow-up care for the patient

Appendix 16: Healthcare professionals Analytical Framework

1. Background
1.01 Aim of Role
1.02 Role Satisfaction
1.03 Caseload - new patients
1.04 Supports the need for carer study
1.05 Personal experience of being a carer
1.06 Dissatisfaction with role
1.07 Emotional Work
1.08 Role has changed

2. Carers
2.01 How HPs define carer?
2.02 Who chooses the carer?
2.03 Contact with Carers
2.04 Acknowledgement of the importance of the role
2.05 Gender issues of caring
2.06 Term not familiar to them

3. HPs perspectives of what carers do
3.01 'A pair of ears'
3.02 Monitor and Manage Side-effects and Symptoms
3.03 Protector 'A safety net'
3.04 Information Gatherer
3.05 Information Processor
3.06 Complainer
3.07 Advocates
3.08 Links between patient and hospital
3.09 Role adopters
3.10 Practical Helpers
3.11 Providers of Emotional Support
3.12 Planners
3.13 Team member
3.14 24-7 support
3.15 Enablers of treatment
3.16 End of life discussions-decisions
3.17 Manage medicines
3.18 Make decisions when patients can’t
3.19 They see the good and the bad
3.20 Do not think they provide emotional support
3.22 Depends on the needs of the patient
3.23 Good prompters like a P.A.

4. HPs Perceptions of Carers Information Needs
4.01 Info about side-effects
4.02 Need to understand the information
4.03 Contact Numbers
4.04 Signposting to other resources

4.05 Prognosis information
4.06 They need to know what they can do
4.07 Need to be prepared
4.08 The information source needs to be reliable
4.09 Good prompters like a P.A.

5. Other Needs

5.01 To know what they can do
5.01 Acknowledgement
5.02 The best for their loved ones
5.03 Need to be able to communicate-translate to healthcare professionals
5.04 When the carers are children or teenagers
5.05 Need to come to terms with the diagnosis
5.06 Need permission to be involved
5.07 They need to be needed
5.08 They need to feel safe
5.09 They need reassurance
5.10 They need to tell their story
5.11 They need support
5.12 Permission to have a break or live their own lives

6. Perceptions of carers challenges
6.01 Perceptions of ICs' challenges or difficulties
6.02 Geographical proximity
6.03 Communicating with Healthcare professionals
6.04 They do not know what to do
6.05 Managing other commitments e.g. work
6.06 Being open with the patient
6.07 Information overload
6.08 Their emotions
6.09 Impact on life
6.10 Adapting to new roles
6.11 Patients worrying about the carer
6.12 Financial worries
6.13 Understanding medical knowledge
6.14 Relationship difficulties
6.15 Managing Crisis
6.16 Patients perceptions of the carer's role
6.17 Understanding the Organisation & Roles
6.18 Their health
6.19 Multiple caring responsibilities
6.20 Managing the fluctuations good days & bad
6.21 Managing the patient's diet
6.22 Parking
6.23 Uncertainty
6.24 Need to play it the patient’s way
6.25 Patients block info or involvement
6.26 Understanding what is normal and what is not
6.27 Managing medications and oral chemo

6.28 Past experiences
6.29 Have the same reactions as patients
6.30 They walk on egg-shells
6.31 It’s hard for them to see the patient being ill
6.32 It goes on for a long time
6.33 Put the patients’ needs first

7. HPs current realities of working with patients & carers

7.01 Identification of the patient's support person
7.02 Providers of information
7.03 Organisation of work
7.04 Team Working
7.05 Patient assessment
7.06 Focus on treatment delivery rather than patients
7.07 Staff are knowledgeable
7.08 It's a difficult job for HPs
7.09 Important Role of CNS
7.10 Perceptions of how support to carers is pro
7.11 ICs are a resource
7.12 Negotiating the carer role
7.13 The pre-chemo workup or 'chat'
    7.13.01 Where the pre-chemo workup happens
    7.13.02 The purpose of the pre-chemo work-up
    7.13.03 Pre-chemo work-up number of patients
7.14 Carers current role in consultations
7.15 Who supports patients and families when having chemo
7.16 Telephone work
7.17 HPs do a good job
7.18 Carers influence treatment decisions
7.19 Sharing information with other HPs
7.20 What a doing a good job means
7.21 HPs perceptions of each others' roles
7.21 Prioritising needs, workload is a constant battle
7.22 Have relationships with patients and their families
7.23 Get to know patients & carers over time
    7.24 Carers have more support when the patient is dying
    7.25 Patient centred care
    7.26 Do not have a shared philosophy
    7.27 Patient are often more open with nurses
    7.28 Learn from Role Models & Experience
    7.29 Do not tell the carers how important they are
    7.30 Time and learning the ropes
    7.31 We look after the patients
    7.32 Important to welcome patients
    7.33 A lot of administration
    7.34 Humour
    7.35 Douglas Macmillan unit
    7.36 When the patient is having their drugs
    7.37 Support groups: formal and informal
    7.38 CAB

7.39 Chaplain
7.40 Hospice

8. Complaints
8.01 Who Complains?
8.02 Why do they complain?

9. Whose role and responsibility is it to support carers?

9.01 Should HPs be supporting carers?
9.02 Everybody’s Role?
9.03 Doctors
9.04 Nurses
9.05 CNS
9.06 Key worker
9.07 Support workers
9.08 Lack of clarity around who is responsible
9.09 The role of MDTs
9.10 Carers GP
9.11 Allied healthcare professionals e.g. dietician

10.0 HPs Challenges – Patient & Carer issues
10.01 Health Literacy
10.02 The Carers' Role not clearly defined
10.03 Managing different expectations
10.04 Some patients do not have anyone or limited support
10.05 Age of patient
10.06 Difficult conversations with carers
10.07 Difficult conversations with patients
10.08 Independent Patients
10.09 Some patients won't seek help or engage
10.10 Patients who ignore advice or information
10.11 Why patients or carers ignore the advice or information
10.12 Geographical location
10.13 Patients protect their families
10.14 Patients at risk
10.15 Pts or carers do not know what to expect or
10.16 Independent carers
10.17 The transition to palliative care
10.18 If the family member is a health profession
10.19 Patients and Carers have different info needs
10.20 Everyone is different
10.21 Power difference when carers know more
10.22 Difficult family dynamics
10.23 Families who live far away
10.24 Needy - difficult patients - carers
10.25 Socio-economic status of patients & carer
10.26 Understanding the family dynamics
10.27 If the carers are not involved from the beginning

10.28 The carer is not always who you think it will be
10.29 Some people cannot take on the carer role
10.30 Some patients are not always honest
10.31 Cultural issues
10.32 Patients want the treatment
10.33 Do not want to keep coming to the hospital
10.34 Do not really know what is going on at home
10.35 Patients want to keep things normal

11.0 HPs Challenges - Organisational & Treatment Issues
11.01 Difficult systems
11.02 The environment
11.03 Capacity
11.04 Merger
11.05 Amount and complexity of info
11.06 Timing of information provision
11.07 Impact of ambulatory changes in delivery
11.08 Technical procedures
11.09 No resources
11.10 Complex and lengthy treatments
11.11 Medical Teams
11.12 Macmillan Douglas Centre
11.13 Counter-productive actions of others
11.14 Different Perspectives & Approaches of Staff
11.15 Gaps in the service
11.16 GPs & other HPs
11.17 Checklist and organisation of assessment
11.18 Finances
11.19 Patients in non-specialist areas
11.20 Need to be safe
11.21 Treatment in advanced disease
11.22 Peer Review
11.23 Timing between diagnosis and treatment

12.0 HPs Challenges - HP Issues

12.01 Conflict between staff
12.02 Duty of care is to the patient
12.03 Managing different expectations
12.04 'Opening the can of worms'
12.05 Being time pressured
12.06 We are in the 'frontline' dealing with complaints
12.07 Frustration at not knowing how to help
12.08 Confidentiality
12.09 Managing boundaries
12.10 The challenges of learning about the technical side
12.11 Being recognised for what nurses do
12.12 Different role perceptions
12.13 Do not know how to approach carers
12.14 Do not know or has little insight

12.15 Emotional Work
12.16 Always on show

13.0 Perceived Barriers to Providing Support to Carers
13.01 The Patient
13.02 Time and 'busyness'
13.03 Lack of resources
13.04 No Training
13.05 Not having the skills
13.06 Limited experience
13.07 Attitudes
13.08 The MDT
13.09 Not having a shared philosophy
13.10 Professionals understanding of the carer role
13.11 No parameters
13.12 Service-staff focused on delivery
13.13 Supporting carers not valued by the organisation
13.14 No monetary rewards or value not easily measure
13.15 Organisation doesn't value the therapeutic work of the nurse
13.16 'Opening the can of worms'
13.17 The carers themselves
13.18 Staff do not recognise the need
13.19 Not enough staff
13.20 Not having the organisational systems to support
13.21 Resistance to change
13.22 Communication between teams HPs
14.0 What HPs think should be happening

14.01 Holistic Care
14.02 Assessment
14.03 Effective Communication
14.04 Recognition of the carer role
14.05 Including and acknowledging the carer
14.06 Therapeutic Relationships
14.07 Having boundaries, clearly defined relations
14.08 Prioritising the workload
14.09 Signposting carers
14.10 Key-worker role
14.11 Continuing professional development
14.12 Being professional, having the right attitude
14.13 Continuity of Care
14.14 Educating
14.15Need to review what we are doing honestly
14.16 Working together – giving the same message
14.17 Need to empower people
14.18 Patients have a good experience of care

15.0 What would help?
15.01 Leadership
15.02 Having assessment and or communication

15.03 Being honest and brave
15.04 Time management skills
15.05 Skills for exploring family dynamics
15.06 Access to professional development – education
15.07 Defined parameters or set boundaries
15.08 Balancing the workload
15.09 Identifying the patients main supporter
15.10 Recognising the role of the IC as a resource
15.11 Better methods of providing or managing the information
15.12 Signposting and encouraging to other avenues of support
15.13 Knowing the available resources
15.14 Having someone on site to help with finance
15.15 Market ourselves better and value what we do
15.16 Utilising what we have more effectively e.g. time
15.17 Information Prescriptions
15.18 Strategies on how to engage with carers
15.19 The intervention needs to be simple
15.20 Understanding what other HPs do with carers
15.21 Easier when the carer understands
15.22 Educating the carer
15.23 Exploring family dynamics at the beginning
15.24 Formal guidelines
15.25 Listening to and having a conversation with carers
15.26 Being more proactive
15.27 Having positive role models
15.28 Having a key support person
15.29 Documentation
15.30 Having a shared understanding
15.31 Better methods for sharing information with each other
15.32 Exploring patients and carers previous experience
15.33 Assessment for carers
15.34 Improve patient care
15.35 Being good enough
15.36 Support each other
15.37 Nurse Led Clinics
15.38 People write things down

16.0 The benefits of engaging with carers

16.01 Better patient care
16.02 Could avoid a crisis
16.03 Increased role satisfaction
16.04 Could avoid complaints
16.05 Carers would be more involved in carer
16.06 Enable patients to have chemo safely
16.07 Carers would save us time

17.0 How HPs could intervene in an ideal world

17.01 Support groups

17.02 Better Management of Macmillan Douglas
17.03 More staff
17.04 DVD for carers
17.05 Give carers a pre-chemo consultation
17.06 Have a dedicated phone line
17.07 Education session clinic
17.08 A better environment
17.09 Assessing carer needs
17.10 Carer involvement forum/workshop
17.11 In house information unit.
7.12 Transparency of information for end of life care
7.13 Complimentary therapies
7.14 Healthcare professionals were more empathetic
7.15 A health professional just for carers
7.16 Easy referral to CAB

Appendix 17: Patients Analytical Framework

1.0 Context –Background

- 1.01 Employment
- 1.02 Commitments
- 1.03 Family
- 1.04 Previous cancer experiences
- 1.05 Illness trajectory
  - 1.05.1 Pre-diagnosis
  - 1.05.2 Time since diagnosed
  - 1.05.3 Treatment trajectory

2.0 Impact of Diagnosis

- 2.01 How it felt when diagnosed

3.0 Perceptions of chemotherapy (initially)

- 3.01 Pre-conceived ideas
- 3.02 Media
- 3.03 Side effect worries

4.0 Actual experience of chemotherapy

- 4.01 Reality different from perceptions
- 4.02 Experience of side-effects
- 4.03 Adverse events
- 4.04 Life revolves around treatment
- 4.05 I got off lightly
- 4.06 Takes over your whole body
- 4.07 Fatigue
- 4.08 Surprised by later effects
- 4.09 Impact on life
- 4.10 Impact on work
- 4.11 Impact on relationships
- 4.12 have good days and bad days
- 4.13 Impact on body image
- 4.14 Financial impact
- 4.15 'The worst bit'
- 4.16 Need to take control
- 4.17 Need to get on with it
- 4.18 Impact on emotions
- 4.19 Time has gone quickly
- 4.20 Open with people

5.0 Preparation for Treatment

- 5.01 Did they feel prepared?
- 5.02 Nothing could prepare you
- 5.03 Information received
- 5.04 Information overload
- 5.05 Other sources of information?
- 5.06 Didn't want to know too much
- 5.07 Everybody is different
- 5.08 Wanted to take it as it comes
- 5.09 The internet

6.0 Appointments and Treatment

- 6.1 Pre-chemotherapy consultation
  - 6.1.1 Block carers questions
  - 6.1.2 Do not remember it or the info provided
  - 6.1.3 They didn't tailor the information

- 6.2 Having someone with them
- 6.3 Not having someone with them
- 6.4 Supportive people's role when at the hospital
- 6.5 Reasons for not having someone with them
  - 6.5.1 Do not want to be burden
  - 6.5.2 Would have to entertain them
  - 6.5.3 My disease – need to have control
  - 6.5.4 Childcare
  - 6.5.5 They were at work
  - 6.5.6 Carer didn't want to come in

- 6.6 Did they ask about your carer or support at home?
- 6.7 Seeking advice from the service
- 6.8 Assessment or a tick-box exercise

7.0 Perceptions of the service

- 7.01 Environment
- 7.02 How they perceived the service
- 7.03 How the service supported them
- 7.04 Welcoming
- 7.05 They know me
- 7.07 Support workers
- 7.07 The nurses
- 7.08 The CNS role
- 7.09 The Doctors
- 7.10 The difference between in-patient and outpatient care
- 7.11 Who (HP) they talk about
- 7.12 Humour
- 7.13 Staff being positive
- 7.14 Staff maintaining normality
- 7.15 Do staff acknowledge family/friends

7.16 They listen to you
7.17 They are under pressure
7.18 Didn’t offer emotional support
7.19 They make me feel safe
7.20 Have a relationship with staff
7.21 Trusted the HPs
7.22 Didn’t know who the CNS was
7.23 The merger

8.0 Perceptions of the role family/friends
8.01 Who they define as their main support person
8.02 Different people support in different ways
8.03 Lucky to have them

9.0 Support family and friends provide

9.01 Protect
9.02 Practical
9.03 Emotional
9.04 Fun
9.05 Normality
9.06 Child-care
9.07 Information gatherer
9.08 Information provider
9.09 Blunting the effects e.g. body image
9.10 Driver
9.11 Being in it together
9.12 Information processor

10.0 Perceptions of carers challenges
10.1 They do not really understand
10.2 It hits them harder
10.3 Negotiate roles
10.4 Learn new roles
10.5 Protect the patient
10.6 They worry more
10.7 They do not know what to do
10.8 Food
10.9 Carers being assertive
10.10 They need to be needed
10.11 They need to support
10.12 Their emotions
10.13 I block their involvement
10.14 Impacts on them

11.0 Patients challenges involving family/friends

- 11.1 My disease – the need for control
- 11.2 I need to protect them
- 11.3 I do not want to burden them
- 11.4 I need my space
- 11.5 I am independent
- 11.6 I do not want to talk to people about it
- 11.7 I can talk for myself
- 11.8 I want to carry on as normal
- 11.9 I wasn't aware of what was going on
- 11.10 I help them
- 11.11 Talking about prognosis
- 11.12 I need to pretend everything is ok

12.0 Other Challenges for patients

- 12.1 I do not like people knowing
- 12.2 Reactions of others
- 12.3 Being open with people
- 12.4 I had to work – no money
- 12.5 Childcare
- 12.6 Sorting out finances
- 12.7 End of treatment
- 12.8 Food

13.0 What helped patients

- 13.1 My colleagues
- 13.2 My friends
- 13.3 Being reassured by HPs
- 13.4 Being able to be totally open with HPs without family around
- 13.5 Being open with people
- 13.6 Continuity and being known
- 13.7 Do what the HPs say

14.0 Support for family and friends –what would help

- 14.1 Found it hard to come up with anything
- 14.2 There are places they can go
- 14.3 Someone to talk too
- 14.4 Me being ok
- 14.5 To know what to do or expect
- 14.6 Being included

15.0 Problems with service

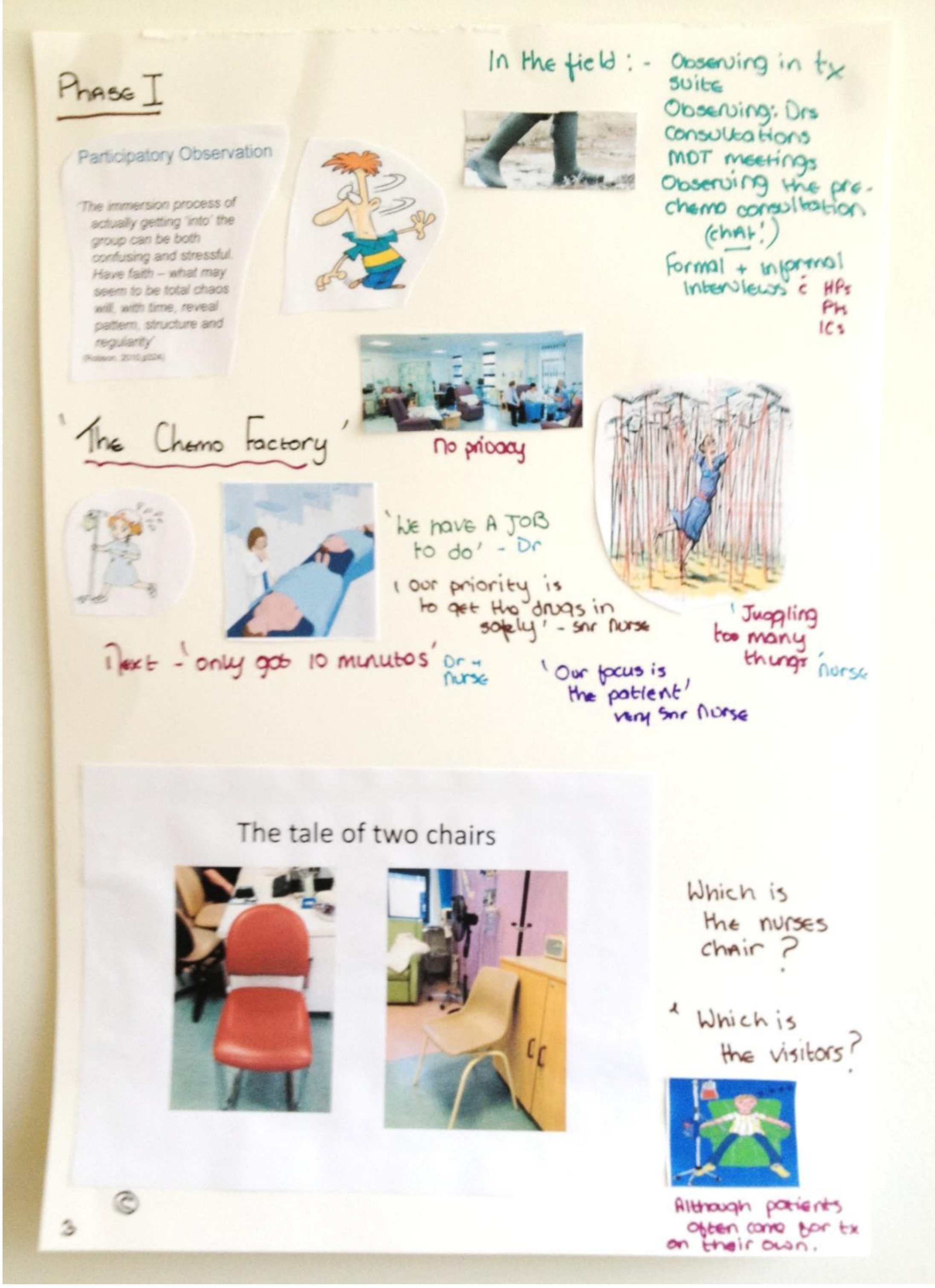
- 15.01 Waiting times
- 15.02 Ask the same questions no continuity

- 15.03 HPs made assumptions
- 15.04 Traveling to other centres
- 15.05 Busyness
- 15.06 Not being seen by someone who knows you
- 15.07 Communication between departments
- 15.08 Weekends

16.0 What would help or be improved in the service

- 16.01 Better ways to provide the information
- 16.2 Point out the main side-effects rather than all
- 16.3 Help with finances and benefits

Appendix 18: Examples of ‘Story Boards’



Phase I

Participatory Observation

‘The immersion process of actually getting ‘into’ the group can be both confusing and stressful. Have faith – what may seem to be total chaos will, with time, reveal pattern, structure and regularity’

(Robson, 2010,p324)

In the field :- Observing in tx suite
Observing: Drs consultations
MDT meetings
Observing the pre-chemo consultation (chat!)
Formal + informal interviews c̄ HPs
PTs
ICs

‘The Chemo Factory’

No privacy

‘We have A JOB to do’ - Dr

‘Our priority is to get the drugs in safely’ - Snr Nurse

‘Juggling too many things’ Nurse

Next - ‘only got 10 minutes’ Dr + Nurse

‘Our focus is the patient’ very Snr Nurse

The tale of two chairs

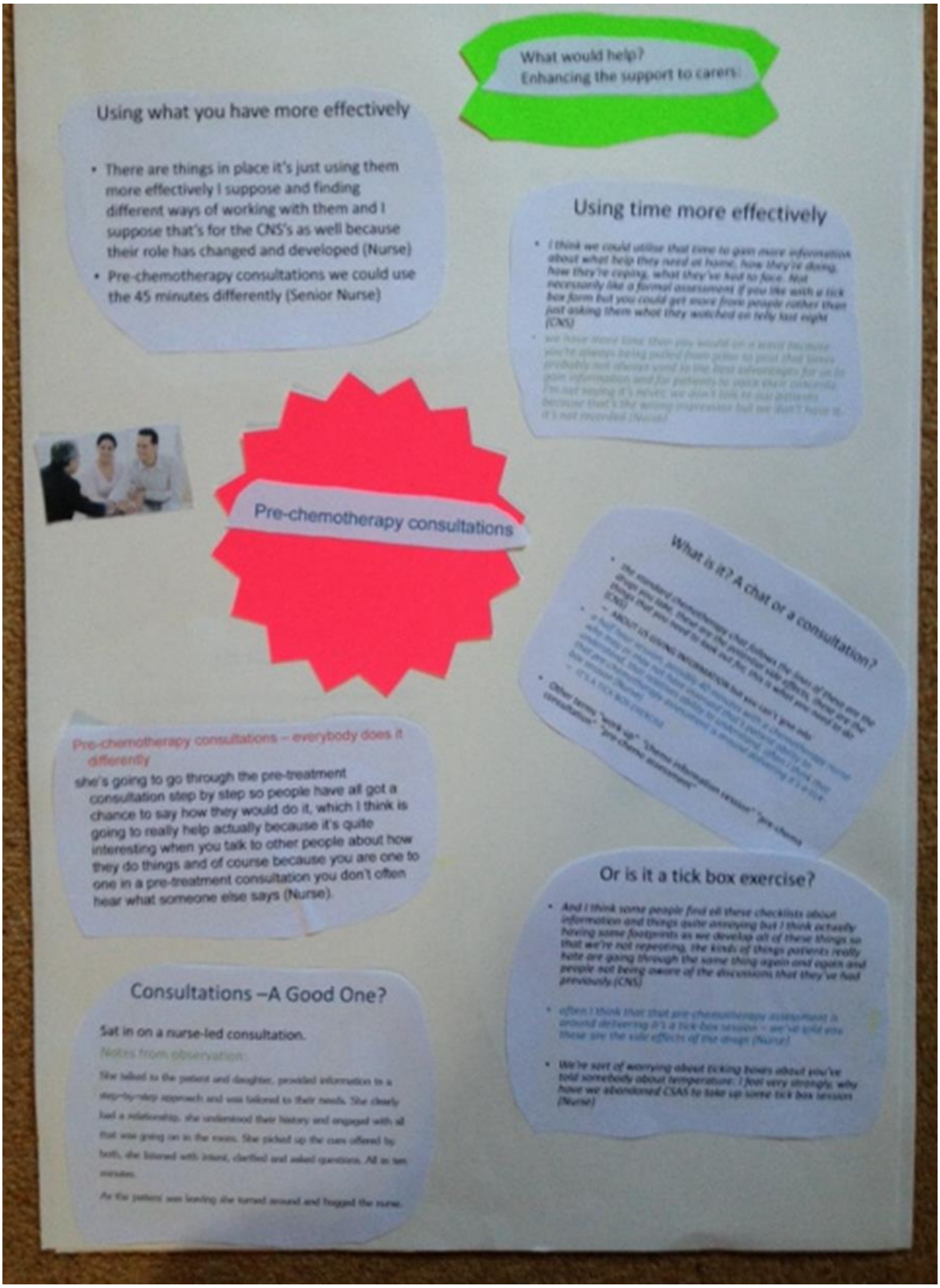
Which is the nurses chair?

Which is the visitors?

Although patients often come for tx on their own.

©

3



What would help?
Enhancing the support to carers

Using what you have more effectively

- There are things in place it's just using them more effectively I suppose and finding different ways of working with them and I suppose that's for the CNS's as well because their role has changed and developed (Nurse)
- Pre-chemotherapy consultations we could use the 45 minutes differently (Senior Nurse)

Using time more effectively

- *I think we could utilise that time to gain more information about what help they need at home, how they're doing, how they're coping, what they've had to face. Not necessarily like a formal assessment if you like with a tick box form but you could get more from people rather than just asking them what they watched on telly last night (CNS)*
- *we have more time than you would on a ward because you're always being pulled from pillar to post that time's probably not always used to the best advantages for us to gain information and for patients to voice their concerns. I'm not saying it's never, we don't talk to our patients because that's the wrong impression but we don't have it, it's not recorded (Nurse)*

Pre-chemotherapy consultations

What is it? A chat or a consultation?

- *the standard chemotherapy chat follows the lines of these are the drugs you take, these are the potential side effects, these are the things that you need to look out for, this is what you need to do (CNS)*
- *– ABOUT US GIVING INFORMATION but you can't give info* [illegible]
  – IT'S A TICK BOX EXERCISE
- Other terms "work up" "chemo information session" "pre-chemo consultation" "pre-chemo assessment"

Pre-chemotherapy consultations – everybody does it differently

she's going to go through the pre-treatment consultation step by step so people have all got a chance to say how they would do it, which I think is going to really help actually because it's quite interesting when you talk to other people about how they do things and of course because you are one to one in a pre-treatment consultation you don't often hear what someone else says (Nurse).

Or is it a tick box exercise?

- *And I think some people find all these checklists about information and things quite annoying but I think actually having some footprints as we develop all of these things so that we're not repeating, the kinds of things patients really hate are going through the same thing again and again and people not being aware of the discussions that they've had previously (CNS)*
- *often I think that that pre-chemotherapy assessment is around delivering it's a tick box session – we've told you these are the side effects of the drugs (Nurse)*
- *We're sort of worrying about ticking boxes about you've told somebody about temperature. I feel very strongly, why have we abandoned CSAS to take up some tick box session (Nurse)*

Consultations –A Good One?

Sat in on a nurse-led consultation.

Notes from observation:

She talked to the patient and daughter, provided information in a step-by-step approach and was tailored to their needs. She clearly had a relationship, she understood their history and engaged with all that was going on in the room. She picked up the cues offered by both, she listened with intent, clarified and asked questions. All in ten minutes.

As the patient was leaving she turned around and hugged the nurse.

Appendix 19: The Support Notebook

Are you supporting someone who is receiving chemotherapy treatment?

SUPPORT NOTEBOOK

This notebook may be used to write down your questions, take notes during or after

While chemotherapy is often administered in hospital, much of the job of managing symptoms that can accompany chemotherapy falls to the person with cancer and also in many cases to family and friends. Family and friends are very important in helping patients to stay safe and well.

This notebook is a resource and record for those who are supporting or caring for people undergoing chemotherapy treatment

Who can help if you need general advice about the patients' chemotherapy treatment and symptoms?

Who can help?	Contact details	
IN A MEDICAL EMERGENCY	**TELEPHONE 999**	
[redacted] Chemotherapy Treatment Suite **THIS IS THE ALERT NUMBER IN OFFICE HOURS**	Unit Sister or Treatment Suite nursing staff (01[redacted] (01	
[redacted] Inpatient Ward **THIS IS THE ALERT NUMBER OUT OF OFFICE HOURS**	Ward Sister or nurse in charge (01[redacted]	
The Keyworker (This is often the Clinical Nurse Specialist for the type of cancer that is being treated)	Keyworker: Contact details:	
Hospital Consultant	Name:	
[redacted] Outpatient Department Reception	(01[redacted]	
Macmillan Cancer Support	Ask Macmillan 0808 808 00 00	www.macmillan.org.uk Macmillan Cancer Support 89 Albert Embankment London SE1 7UQ

What to do if a chemotherapy patient is unwell at home

Not all patients become unwell during chemotherapy treatment, but some will experience *symptoms* or *side-effects*.

There are many reasons you may need to contact the hospital for urgent advice. Some (but not all) reasons are listed below. All patients are advised to have a working **thermometer** at home so they can easily check their temperature if they feel unwell.

Phone the numbers on the 24 hour advice ALERT card if the patient is unwell or has one or more of these symptoms:

- A temperature above 37.5 ·c or below 36·c
- Feeling cold or shivery or generally unwell
- Coughing up green sputum
- Persistent diarrhoea
- Persistent nausea and/or vomiting
- Have other symptoms which relate to chemotherapy side-effects

Even if the symptoms are mild we would still prefer patients and family / carers to ring for advice.

If you or the patient calls for advice, the nurse will ask you a series of questions to help them assess the problem and guide the advice they give.

What information will the doctors and nurses need at each appointment?

When patients are reviewed before starting chemotherapy, and prior to each session of chemotherapy, there are some key questions that the team will discuss with the patient.

It may be helpful to write down anything you think might be important to mention in clinic at the time it occurs. The doctors and nurses are particularly interested in the following:

- **Have there been any infections / temperatures since the last appointment?**
    - If so did you contact anyone for advice?
    - If so, who from?
    - What advice/treatment did the patient receive for the infection?

____
____
____
____

- **Have there been any side effects from the chemotherapy treatment since the last appointment?**
    - How long did the side effects last?
    - How severe were they?
    - Did the side effect interfere with daily life?
    - If so did you contact anyone for advice?
    - If so, who from?
    - What advice/treatment did the patient receive for the side effect?

____
____
____
____

- **Have there been any new symptoms or have symptoms got worse?**

____
____
____
____

- **How are you, patient / family / friends, managing with treatment and the changes this brings to home life?**

These may be *practical changes* e.g. childcare, working arrangements, travel issues and/or *emotional / psychological changes* e.g. anxiety, depression, issues relating to sex, mood changes

____
____
____
____

- **Have there been any changes since the last appointment that could affect treatment or how you are managing at home?**

____
____
____
____

- **Are there any other questions or anything you wish to discuss?**

____
____
____
____

(New page)

Date

____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____
____

Appendix 20: Training

Training	Purpose	Year One: 2011	Year Two: 2012	Year Three: 2013
Supervision	Supervisory support	→		
Advanced Qualitative Methods for Healthcare Research		Jan		
Advanced Quantitative Methods for Healthcare Research			Sept/ Oct	
Organisation Development: Doctoral in Healthcare Research Module	Gain an understanding of organisations, management of change and people.		May & June	
NatCen Intro to Framework Software/NVIVO			Oct 4	
NatCen Reporting Qualitative Data			Dec 12	
NatCen Interviewing Skills	Opportunity to understand more and practice interviewing skills.	Sept 21, 22		
Leading Empowered Organisations LEO	Leadership and managing change with a particular emphasis on personal skills			June 1, 2
Scriptoria Training: KCL	Writing for publication skills	Sept 7, 8		
NIHR Writing for Publications Oxford University	How to write for your target publication			June 6
Literary Fellow Support: KCL	Guidance and support for writing skills			Mar 18 May 20
Participatory Research Brighton University	Introductory course to participatory methods		July 31	
Bromley Carers Association	Training for healthcare professionals working with carers.	July 27		
PPI – King's Health Partners	Getting involved in research guidance for non-professionals		Feb 28	
NIHR Workshop PPI – Birmingham University	Involving patients and public in research guidance for researchers	July 19		
Holistic Needs Assessment Training - SLHT	Introduction to the HNA and skills		Apr 11	
SAGE & THYME Training GSTFT	Introduction to managing distressing conversations	Dec 13		
Professional Coaching– 5 sessions	Intensive sessions aimed to focus on personal skills for managing myself and others especially at a strategic level		May-Sept	
Action Research Course University of Ulster	Opportunity to learn more about action research – underpinning philosophies and creative strategies for involving		June 18-20	

Training	**Purpose**	**Year One: 2011**	**Year Two: 2012**	**Year Three: 2013**
	participants			
Complex Interventions Training KCL	Overview of complex interventions and how to evaluate			May 22
KCL Skills Forge				
Microsoft Word 2007	Managing long documents for theses			May 21
Microsoft Word 2007 - Excel	Gained excel experience to design matrices for interview framework analysis	April 5		
Fundamentals of Assertiveness	Increase assertiveness and managing conflict skills	Mar 7		
Writing a literature review		May 10		
Information Retrieval for Health	Skills for searching the literature and databases	Feb 17		
Conferences & Seminars				
NIHR Training Meetings	Opportunity to meet other research fellows, network and learn about different research skills	Sept 19,20	Nov 21, 22	Nov 26, 27
Mixed Methods Conference: Leeds University	Network and learn more about mixed-methods	June 7-9		

Appendix 21: Conference and Event Presentations

Event/Conference	**Date And Place**	**Title Of Presentation**	**Audience**
"Research Matters"	May 21, 2012 South London Healthcare Trust	Developing interventions to prepare and support carers in the chemotherapy treatment setting	Mostly Doctors and Associated Healthcare professionals (AHPS)
British Psychosocial Oncology Society: Annual Conference	January 17, 2013 Southampton	'Time to think about Carers': Preparing and meeting the needs of family and friends who support people having chemotherapy	Mostly healthcare professionals /researchers who have an interest in psychosocial oncology
Seminar Emotions group	January 28, 2013 University of Surrey	The emotions involved: Time to think about carers	Mostly academics and researchers who were interested in emotional management
CNS Meeting	June 17, 2013	'Time to think about Carers': Preparing and meeting the needs of family and friends who support people having chemotherapy – What needs to be done?	Nurse managers and CNSs working across research sites
Multi-national Association Supportive Cancer Care: Conference	June 27-29, 2013 Berlin	'Time to think about carers'	International audience, doctors, nurses and AHPs who work in Supportive Cancer Care
Research and Development Event	July 6, 2014 King's College Hospital	'Time to think about carers'	Mostly nurses working within KCH
UKONS Education Event	October 13, 2014 Hosted by Guy's and St Thomas Foundation NHS Trust and King's College London	Carers: Valuable yet undervalued?	Nurses and AHPs working at all levels in cancer services across London