University of Chester

This work has been submitted to ChesterRep – the University of Chester's online research repository

http://chesterrep.openrepository.com

Author(s): Helen Claire Boothman

Title: A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists in a District General Hospital

Date: March 2014

Originally published as: University of Chester MSc dissertation

Example citation: Boothman, H.C. (2014). *A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists in a District General Hospital*. (Unpublished master's thesis). University of Chester, United Kingdom.

Version of item: Submitted version

Available at: http://hdl.handle.net/10034/325961

NM 7059 Dissertation

Master of Science in Professional Studies

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists in a District General Hospital.

Dissertation submitted to the University of Chester for the Degree of Master of Science in Professional Studies in part fulfilment of the Modular Programme in Professional Studies,

By

Helen Claire Boothman

Assessment number: H12333

March 2014

Abstract

Research Question
'What factors influence the vocabulary Clinical Nurse Specialists (CNS) in a District General Hospital (DGH) use when communicating with people with cancer?'

Context and Previous Research
There are 1.6 million people living with a diagnosis of cancer. A plethora of reports and studies have demonstrated that effective communication between health professionals and patients forms the foundation for caring for people with cancer. Effective communication has been shown to reduce levels of depression and anxiety, improve levels of self-esteem and well-being, reduce psychological morbidity and increase survival. Despite this there are ongoing concerns regarding the language used by health professions and the impacts on people with cancer.
The literature search reveals there is research available concerning the language used by professionals and the effect upon people with cancer however there does not appear to be any research on factors that have influenced the vocabulary and language used.

Sample and Setting
The sample population consists of 14 CNS's across a range of cancer specialities. All 14 CNS's were invited to participate; the eight respondents form the study sample. The setting is a DGH in the North West of England.

Data Collection and Analysis
Qualitative data was collected via digitally recorded semi-structured interviews using an interview guide. The recordings were transcribed verbatim and analysed using the framework of Cohen, Kahn and Steeves.

Findings
Four broad themes representing four key factors that influence CNS's vocabulary emerged; people with cancer, personal, process and publicity. Each of the four themes encompasses sub themes. 'People with cancer' includes the vocabulary of people with cancer, non-verbal language, narrative and the influence of relatives. The 'personal experience' of the CNS includes level of experience in the role, knowledge of speciality, confidence, personal experience of cancer, reflection and listening and learning. The third theme 'process' includes themes concerning consultants, stage of the patient journey, training courses, cancer type, environment, terminology, policy and team working. The fourth theme 'publicity' includes the influence media awareness, the internet and literature.

Conclusion
The study reveals multiple factors influence the vocabulary CNS's in a DGH use when communicating with people with cancer. The study provides new insight into how CNS's form and choose their vocabulary in response to the stimuli and influences of the people they care for and work with. The findings reveal new data on the interaction and interconnectedness of the experience, knowledge and confidence of the CNS and how these factors influence vocabulary and communications with people with cancer.

<u>Declaration</u>

The work is original and has not been submitted previously in support of any qualification or course.

…………………………………………………….

Helen C Boothman

Word count: 16 385
(The word count includes the abstract but excludes the declaration, acknowledgments, table of contents and list of abbreviations)

Acknowledgments

APPENDICIES		PAGE
Appendix 1	Key concepts and words for literature search and narrowing techniques used	84
Appendix 2	Interview guide	85
Appendix 3	Invitation to participate letter	87
Appendix 4	Participant information sheet	89
Appendix 5	Consent form	91
Appendix 6	Confirmation letter of unsuccessful selection to participate	92
Appendix 7	Confirmation letter of participation	93
Appendix 8	University of Chester ethical approval letter	94
Appendix 9	DGH research project approval letter	95

List of abbreviations

ACST	Advanced Communication Skills Training
BCC	Breast Cancer Care
CRUK	Cancer Research UK
CNS	Clinical Nurse Specialist
DGH	District General Hospital
DH	Department of Health
HP	Health Professional
IPL	Invitation to Participate Letter
IV	Interviewee
MDT	Multi Disciplinary Team
NHS	National Health Service
NPSA	National Patient Safety Agency
PIS	Participant Information Sheet
REC	Research Ethics Committee
RGF	Research Governance Framework
UC	University of Chester
UK	United Kingdom

CHAPTER 1

Introduction

Drawing on the evidence base and personal experience as a Clinical Nurse Specialist (CNS) this research study explores the question 'What factors influence the vocabulary CNS's in a District General Hospital (DGH) use when communicating with people with cancer?'. The research is grounded in the naturalistic paradigm, using a qualitative approach and phenomenology as a framework. Data has been collected using semi-structured interviews with eight CNS's from a DGH in the North West of England. The data has been analysed using the Heidegerrian framework of Cohen, Kahn and Steeves (2000).

Background and Rationale

In 2000 the National Health Service (NHS) Cancer Plan stated that over 200,000 people were diagnosed with cancer each year (Department of Health (DH), 2000a). Recent data from Cancer Research UK (CRUK) shows this figure increased to 325,000 diagnoses of cancer in 2010 (CRUK, 2013). Since the 1970's there has been a 33% increase in the incidence of cancer in the United Kingdom (UK), with more than one in three people predicted to develop the disease during their lifetime (CRUK, 2013). DH (2011) states that In England there are 1.6 million people living with a diagnosis of cancer with that figure predicted to rise to three million by 2030.

In 2000 the strategy of the Cancer Plan was to ensure better prevention, detection, treatment and care of people with cancer (DH, 2000a). Whilst CRUK figures show the strategy has not reduced the number of people being diagnosed, it has paved the way for the current DH strategy to develop and be concerned with managing cancer as a chronic disease focused on helping people live with and beyond the disease to lead as active and healthy lives as possible (DH, 2011).

A key factor for the shift in strategy has been improvements in the psychosocial understanding of people diagnosed with and living with cancer and in the way people with cancer are communicated with by Health Professionals (HP's). In 1995 the Expert Advisory Group on cancer in the landmark Calman-Hine report established effective communication between patient and HP's as the founding principle in providing care for people with cancer. The principle has been central to the UK developing a world-class cancer service having been a constant feature of DH reports and strategies including the Manual of Cancer Services (DH, 2004), Getting it Right for People with Cancer (DH, 2007a), National Cancer Survivorship Initiative (DH, 2010a) Cancer Reform Strategy (DH, 2007b) and Improving Outcomes: A Strategy for Cancer (DH, 2011).

In 2002 the National Institute for Health and Clinical Excellence stated the benefits to people with cancer of this basic principle included better understanding of the disease, involvement in decision making, reduced levels of depression and anxiety, improved self-esteem and well-being, reduction in psychological morbidity and increased survival. Since 2002 the benefits of this pre-requisite have evolved so that in 2012 the DH's vision is for people living with cancer to be empowered, informed and prepared to live with the long-term effects of cancer (DH, 2010a).

Whilst awareness of and information about cancer and the communication skills of HP's have developed since 1995 there have been ongoing concerns expressed regarding the language used to describe cancer diagnosis, treatment and late 'survivorship'. These concerns were expressed pre Calman-Hine by Susan Sontag in her 1978 seminal work 'Illness as metaphor'. Sontag details the use of military metaphors to describe cancer and its effect upon people and the

atmosphere of fear, mystery and myth this engendered (Sontag, 1991). Sontag attributed this atmosphere to the lack of understanding about the disease and predicted the language of cancer would evolve when the disease was better understood and survival rates improved.

It could be argued that the language of cancer in practice has evolved from the use of the militaristic metaphors described by Sontag, however metaphors and euphemisms continue to be used in cancer communications. A qualitative study by Appleton and Flynn (2012) reveals the use of metaphors by HP's and the reaction of people with cancer to them whilst a qualitative study by Lanceley and Clark (2013) demonstrates that people with cancer routinely use metaphors as a way of expressing their emotions about and coping with their cancer.

Reisfield and Wilson (2004) suggest the metaphors a patient uses can provide insight into the thought processes underpinning their experience of cancer and can be used by HP's to develop a therapeutic relationship. In turn Reisfield and Wilson argue that metaphors can be a 'time efficient' way for HP's to explain complex medical processes. Kirklin (2007) argues there is a place for 'careful and imaginative' use of metaphors provided they are applied to an individual patient context and situation and not used carte blanch However, Reisfield and Wilson acknowledge the fine line between metaphors promoting greater understanding and being misunderstood and misconstrued. A study by Chapman, Abraham, Jenkins and Fallowfield (2003) found people who did not understand the metaphors and euphemisms used by physicians were impeded in their understanding. Hanne and Hawken (2007) also acknowledge the role of metaphors used by HP's to help explain complex matters and patient's use of metaphors to convey meaning, arguing

4

that Sontag's call not to use metaphors was unrealistic.

There appears to be a dichotomy between HP's use of metaphors and the use of metaphors by people with cancer. As Lanceley and Clark (2012) point out the words and images used can be significant in constructing a person's experience of cancer. In the study by Appleton and Flynn (2012) people with cancer reveal the significance they place on the use of and delivery of words by HP's, the tone and manner in which they are delivered and the impact this has upon them. What HP's say, how they say it and what words are used or not used all contribute to the development and management of their relationship with people with cancer (Appleton and Flynn, 2012). The following serves to demonstrate a personal reflection on this point.

During a simulated interview with Rachel (pseudonym) I used the word 'journey' three times to describe her diagnosis of breast cancer and the treatment plan she would commence. On the third mention Rachel said, "You know, I hate that word…feels like I'm going to Disneyland or going somewhere nice…I'm sure its really helpful for some people…feels a bit like this trauma we're going on". Rachel later modified her descriptor 'trauma' to 'road'.

Reisfield and Wilson (2004) make reference to 'the journey metaphor', suggesting as life is a journey it can be readily applied to cancer as the person moves through an acute to chronic illness. Reisfield and Wilson (2004) offer the view that 'journey' is a neutral word implying neither winning nor loosing but a choice of different roads to go down. Harrington (2012) comments journey is one of the most used metaphors in heath communication. Appleton and Flynn (2012)

researched 'journey' in their study, finding a polarised view. Some people with cancer attached positive meaning to the word accommodating their illness in the 'journey of life'. However, as with Rachel, some people associated 'journey' with enjoyment and pleasure emotions not consistent with cancer. These views together with Rachel's unexpected reaction to my using 'journey' made me consider the vocabulary I was using with people with cancer and reflect on the psychological harm this could cause and the negative impact on my relationships with them.

Appleton and Flynn (2012) point out that words can be interpreted differently by HP's and people with cancer producing positive and negative meanings. In recognition of the importance of language used by HP's and the disparity of understanding of the same word between HP's and people with cancer Appleton and Flynn (2012) recommend further research in this area. The proposed study is a response to this recommendation and recognition of the effect of my words upon Rachel. Research exists concerning what words HP's use and their effect upon people, but this study will explore what factors have influenced the words and vocabulary that HP's use and is entitled, ' A qualitative study to explore factors that influence the vocabulary used by CNS's in a DGH'.

CHAPTER 2

Literature Review

Literature review

The aim of this literature review was to examine the available evidence base on the language and vocabulary used by HP's when communication with and caring for people with cancer. For the research proposal a search was conducted October – November 2012 with updates during March, June and December 2013. The review was written after the data was collected but before data analysis and follows Polit and Beck's (2006) framework. The first stage involved identifying key concepts and words relevant to the topic which were used in different combinations using the Boolean term 'AND' as detailed in appendix 1. Truncation was used to search all variants using '*' at the ends of the words. The searches were refined using the narrowing techniques detailed in appendix 1, using the 'keep search refinements' for each new search. The refinements were used to focus the search on scholarly peer reviewed journal articles written since the publication of the NHS Cancer Plan in 2000, this being a landmark document in the development of communication in cancer care.

The 'library search' facility was used to access a wide range of journals within the same search. The search located 22 articles having relevance to the subject area. Full text was available for 19, the other three requiring the library to source the full text from other sources. Searches using the same techniques conducted on CINAHL, MEDLINE, Blackwell Synergy, Proquest, Lancet, Science Direct and the British Medical Journal databases were unproductive. The University of Chester (UC) library has many cancer and oncology texts however the texts contain theoretical concepts of cancer communications rather than research data. A search of the DH website sourced strategic policy documents rather than research studies. A Macmillan nurse recommended an as yet unpublished qualitative study by

Appleton and Flynn (2012) making 23 pieces in total.

Eight were not research based and whilst not included in the review were useful for broadening understanding of the subject and informing the introduction chapter. Of the remaining 15 research articles five were not as relevant as the title and abstract suggested. The remaining articles do not research the subject matter of this dissertation however they have relevance to the proposed study. The studies are grouped and analysed according to participant type, the 'public' and HP's. Each is critiqued using Steen and Roberts (2011) framework.

Critical analysis of selected literature

Appleton and Flynn's (2012) qualitative study using focus groups with 18 people following cancer treatment, explores how language and metaphors influence adjustment and well-being. The study examines perceptions and understanding of specific words revealing diverse reactions and meanings. The study suggests language is central to the identity of people with cancer. Participants felt the language used at diagnosis was important with ambiguous words and explanations hindering adjustment. Participants familiarity with and knowledge of cancer terminology allowed the language to become normalised, an important part of the acceptance process and management of identity.

Appleton and Flynn conclude the language used by HP's can have negative and positive outcomes for people with cancer. As HP's and lay people's understanding of words used is sometimes different Appleton and Flynn suggest cancer services could benefit from a shift in developing broad communication skills to a specific focus on the language used by HP's (2012). The study is well

constructed and worthy of publication. Use of quotes from participants enlivens the findings and discussion. The study informs this proposal in understanding the views of people with cancer on the language and vocabulary used by HP's and the impact this has on adjustment and well-being. This study supports the recommendation made by Appleton and Flynn for more research in this area.

Using a qualitative phenomenographical approach Friedrichsen, Strang, and Carlsson (2002) explored people with cancer's interpretations of the meaning of words used by doctors when given information about ending cancer treatment. Thirty people with terminal cancer were interviewed using tape-recorded semi-structured interviews. The study identified three groups of words. Indirect warning words or phrases such as 'unfortunately' and 'I'm afraid' used by doctors at the start of the interview to forewarn of the bad news to come, were described by participants as 'fluff' words being ambiguous and confusing. Emotionally trying words and phrases for example 'disease has run its natural course' and 'there's nothing more to do', were described as threatening and abandoning arousing fear and a sense of abandonment. In contrast supporting and fortifying words and phrases including 'We're going to help you…' and 'Now we're going to arrange…' offered support and a feeling the doctor would try and do the best for them.

Dahlgren and Fallsberg's second order perspective analysis was used to examine the conception of what patients said rather than what they actually said. The authors, academics working at a palliative research unit at a Swedish university have interpreted the data to provide valuable insight into the meanings people with terminal cancer give to specific words and phrases used at this juncture of their cancer experience. The results reveal the importance of words, the significance of

which is dependant upon how they are interpreted. The study found people with cancer prefer the use of clear words rather than metaphors or euphemisms. Friedrichsen, Strang, and Carlsson (2002) conclude that doctors need some insight into how the patient perceives words in order to use words they will understand and interpret correctly. As with Appleton and Flynn's study this study highlight the potential for positive and negative outcomes.

Whereas in the above studies participants were people with cancer Chapman, Abraham, Jenkins and Fallowfield (2003) conducted a quantitative study amongst lay people to explore their understanding of the terminology doctor's use in cancer consultations. Chapman, Abraham, Jenkins and Fallowfield selected terms and phrases from 50 videotaped consultations that doctors had with people with cancer. The terms and phrases were incorporated into a questionnaire conducted with 150 people on Brighton beach. Participants were asked to rate how confident they felt about their answers.

Chapman, Abraham, Jenkins and Fallowfield (2003) found the lay population do not understand the terminology used by doctors, citing an example of 50% of participants not understanding that 'tumour is progressing' meant it was spreading. The use of euphemisms and jargon hinders and confuses the correct understanding resulting in differing interpretations of these terms to those intended. Participants were found to overestimate their levels of confidence in understanding the terms.

In conclusion Chapman, Abraham, Jenkins and Fallowfield (2003) suggest people who do not fully understand diagnosis, prognosis and treatment are unlikely to remember what they have been told, will be dissatisfied with their care, and are

unlikely to follow recommendations, all of which can have a negative affect on clinical outcomes and quality of life. This can be remedied by doctors avoiding ambiguous language and medical jargon. Chapman, Abraham, Jenkins and Fallowfield (2003) advocate HP's ask open questions to elicit what has been understood rather than asking 'do you understand?'

Some may argue against the worth of researching terminology amongst lay people however most people diagnosed with cancer are introduced to cancer terminology as a lay person. The study provides a benchmark of the start point in people with cancers understanding of this new language. The study used comprehensive methodology, confidence testing and variance analysis. Chapman, Abraham, Jenkins and Fallowfield (2003) justify the location as having a representative sample of the UK population with the time to complete the questionnaire. However the lack of opportunity to ask questions and the non-contextualised setting are acknowledged limitations of the study.

The latter three studies provide insightful perspectives from the viewpoint and experience of the public with and without a diagnosis of cancer. The remaining seven studies examine aspects of cancer communication and words used by HP's. There is positive and negative resonance between the two groupings.

In a qualitative American study by Siminoff, Graham and Gordon (2006) communication between 405 people with breast cancer and 58 oncologists was observed to explore whether the personal characteristics of patients affect the communication behaviour of oncologists. The study analysed 405 patient-oncologist interactions against six patient and six oncologist variables. The patient variables

were; discussed biomedical matters, discussed psychosocial issues, attempted to build a relationship with the oncologist, a count of questions asked, discussion of emotions and being proactive in raising subjects or offering information. The six oncologist variables were; educates/counsels on biomedical issues, discusses psychosocial issues, asks the patient for information, attempts to build a relationship with the patient, engages with the patient re emotional issues and gathers data relevant to the illness.

The results showed patients who were young, white, better educated with high incomes were given more information and benefited from relationship building communication by the oncologist. However, Siminoff, Graham and Gordon (2006) observed patients with these characteristics volunteered information about themselves and asked the oncologist questions which may explain the improved level of communication by the oncologist. Overall Siminoff, Graham and Gordon (2006) observed that the oncologists followed a repetitive script rather than tailoring their communication to each patient. Ninety-eight percent of the communication was focused on the medical condition with the remaining two percent on emotional and psychosocial issues.

Siminoff, Graham and Gordon (2006) admit to being unclear why the differences in communication arise however they suggest communicative patients provide verbal and non-verbal cues which the oncologist can respond to. Siminoff, Graham and Gordon (2006) recommend oncologists tailor their communication to the patient rather than operating a 'one size fits all' approach.

The objective of a qualitative study by Canadians Thorne, Hislop, Armstrong and Oglov (2007) was to explore whether people with cancer felt communications with a HP played a role in influencing disease outcomes. The study involved 200 people with cancer giving their perspective on what defined helpful and unhelpful HP communication. Thorne, Hislop, Armstrong and Oglov (2003) used qualitative interpretive description methodology to collect the data from the 200 participants over two years via face-to-face, telephone and e-mail open ended interviews and focus groups. Probing techniques were used with participants who expressed a link between communication and outcomes to gather their experience and thoughts. The data was subjected to iterative analysis extracting participant experiences and opinions to interpret the data. Thorne, Hislop, Armstrong and Oglov (2007) identified three ways in which participants felt communication with HP's influenced disease outcomes.

If the person with cancer does not like the HP they are less likely to ask questions and seek help. This is turn can affect their decision making, attitude towards their disease, belief in themselves and ability to survive. Supportive HP's were seen to enhance self belief and engender a positive frame of mind which the participants felt helped them to survive. Participants felt positive communication experiences had a positive effect upon their well-being with involved decision making contributing to a sense of preparedness and psychological well-being. Participants wanted comfort over distress, inclusion over exclusion, clarity over confusion and hope over despair. The negative outcomes of poor and/or unhelpful communication were cited as despair, feeling devalued and dehumanised and psychological distress.

Thorne, Hislop, Armstrong and Oglov (2007) comment that how and what HP's communicate is a powerful influence on a person's capacity to understand what is happening and thereby cope. Thorne, Hislop, Armstrong and Oglov claim HP communication can have a profound effect upon the psychological and attitudinal resources patients muster to achieve positive outcomes for themselves. Thorne, Hislop, Armstrong and Oglov (2007) conclude HP's involved in cancer care are obliged to deliver constructive and supportive communication.

American health academics Rodriguez, Gambino, Butow, Hagerty and Arnold (2007) conducted a qualitative study with 23 people with incurable cancer examining the implicit and explicit language they and their oncologist used when discussing death. The analysis showed 'death' and 'terminal' were used by the oncologist in 52% of encounters. Some participants used explicit words at the start of the encounter showing they were keen to discuss the issue of death straight away. Implicit talk took place in all 23 encounters. Euphemisms and indirect inferences to death used by participants were in the context of discussing how to live their remaining life rather than anticipating their death.

Rodriguez, Gambino, Butow, Hagerty and Arnold (2007) suggest the biomedical model of training oncologists receive influences the language they use and is a barrier to effective communication. However in the oncologists defence, Rodriguez, Gambino, Butow, Hagerty and Arnold (2007) argue each patient has different information needs which can be difficult to establish in the time available. The study concludes that oncologists need more training in communication skills and breaking bad news as they are not meeting patient's expectations resulting in potential negative psychological outcomes.

This study it could be argued is an example of people with cancer approaching the end of their life wanting to focus on positive rather than negative talk to maintain their well-being and positive attitude as echoed in the study by Thorne, Hislop, Armstrong and Oglov (2007). The oncologist's discussions were centred on the biomedical and treatment aspects of the participant's disease with little focus on psychological issues echoing the findings of the study by Siminoff, Graham and Gordon (2006). The study describes how participants find it difficult to understand some of the terminology used stating a preference for the oncologist to use lay language, echoing the work of Appleton and Flynn (2012).

In an exploratory qualitative study in The Netherlands of 100 nurse-patient conversations Utterhoeve, Bensing, Dilven, Donders, deMulda and van Achterberg (2009) investigated the relationship between oncology nurses cue responding behaviour and the satisfaction levels of people with cancer. The ethically approved study used a complex approach. Prior to videotaping the interviews patients were asked to complete a questionnaire assessing their present concerns and measuring their anxiety and depression levels using the Concerns Checklist. Prior to the interview the nurse read the patients charts and then had a twenty minute consultation with the patient. After the interview participants were given a questionnaire to complete then discussed with a researcher whether their concerns had been raised and whether they were satisfied with the nurse's communication.

The study was based on an assumption that people with cancer do not explicitly express their concerns and emotions verbally, preferring instead to use indirect cues indicating something is troubling them. However, the study found the opposite to be true with 70 of the 100 participants being explicit in voicing their

concerns. The study with 34 oncology nurses showed a modest correlation between patient satisfaction levels and the nurse responding to the emotional cues displayed. Utterhoeve, Bensing, Dilven, Donders, deMulda and van Achterberg (2009) acknowledge participants self analysis of satisfaction levels can be subjective with participants responding in the way they think the nurses want them to answer. From the results of the study Utterhoeve, Bensing, Dilven, Donders, deMulda and van Achterberg (2009) suggest culture and ethnicity can influence satisfaction levels recommending more culturally diverse research is done.

Academics Lanceley and Clark (2013) conducted a qualitative study examining the emotional content of nurse's conversations with people with cancer. Analysis of 60 conversations conducted by 21 nurses revealed a depth of imagery, figurative language and metaphor used by people with cancer to describe their feelings and the demands of a cancer illness. Examples include 'a pathetic tale' used by a lady to describe her illness and another lady using the metaphor of the 'build-up' to a sports game as being comparable to her waiting for the doctors ward round. Lanceley and Clark (2013) suggest that for some people with cancer imagery, figurative language and metaphor provides a way for them to express feelings and emotions that would otherwise remain hidden and unexplored.

The study demonstrates how words and images are significant providing insight into the way a person with cancer constructs and deals with the cancer threat. This aspect of cancer communication is important resulting in Lanceley and Clark (2013) calling for nurses to have constant supervision and support available to help them understand and interpret the imagery and metaphors used by people with cancer. The study is very thorough and analytical and one of the few to state ethical

approval was sought and granted.

Razavi, Delvaux, Marchal, Durieux, Farvacques, Dubus and Hogenraad (2002) conducted a quantitative study examining the 'emotional words' 115 oncology nurses used before and after attending a communication skills course. The study used recognised health care dictionaries of words to analyse the data and cross correlate the findings. Whilst the data analysis appears rigorous the 'emotional words' are not detailed in the article which limits the application of the findings. It would have been beneficial to cite the words to establish what they were, provide some form of definition of 'emotional words' and whether there was any commonality. The study showed a modest increase in the use of 'emotional words' by nurses after training which was sustained for about three months. The study reveals low levels of 'emotional content' by nurses and the use of blocking behaviours in response to patient's use of emotional words despite having been on the course.

Razavi, Delvaux, Marchal, Durieux, Farvacques, Dubus and Hogenraad (2002) question whether it is possible to improve HP's empathy skills long term suggesting training should focus on widening the HP's 'emotional word' vocabulary, although as stated examples of such words have not been detailed. Razavi, Delvaux, Marchal, Durieux, Farvacques, Dubus and Hogenraad (2002) could have conducted a qualitative study at set periods following training to explore why participants use of emotional words decreased following training providing useful insight to inform and improve the training course.

A quantitative study by Leadbeater and Beaumont (2010) examined HP's use of words to describe secondary breast cancer. Leadbeater and Beaumont are nurses working for Breast Cancer Care (BCC). The data was gathered via a survey, using the Likert scale to rate terms. The survey was distributed to CNS's and breast care nurses attending a BCC study day. The high response rate of 68% could be attributed to delegates feeling pressured or coerced to partake or could reflect delegates passion about their role and their desire to improve patient care. No tool appears to have been used for the analysis which is best regarded as basic. BCC was using the study to establish if the charity should continue to use 'secondary breast cancer' when communicating with patients, as such the study could be considered to be biased. Leadbeater and Beaumont (2010) acknowledge the responses are subjective based on individual interpretations of what the Likert terms mean.

The study showed 54% of HP's used the term 'secondary breast cancer'. Participants were asked what terms the patient used with 55% saying the patient used the term. Some HP's stated that after using a term they would assess the patient's reaction to it and understanding of it and also look out for and respond to cues the patient gave. Leadbeater and Beaumont (2010) conclude the important factor to consider when using terms is what the patient understands them to mean, the sentiment of the study by Chapman, Abraham, Jenkins and Fallowfield (2003).

:

Summary of analysis

Every effort has been made to locate relevant studies within the timescale available. The studies demonstrate the impact of words and language used by HP's and people with cancer can have on communications, relationships and psychological well-being. Whilst not the main purpose of any of the studies each one indirectly identifies a potential factor that influences HP's choice and use of vocabulary. The review highlights a gap in knowledge concerning factors that influence the vocabulary used by HP's. This study seeks to fill this gap and add to the body of knowledge in the field of cancer communications.

The research question is 'What factors influence the vocabulary CNS's in a DGH use when communicating with people with cancer?' The aim of the research study is to understand factors that influence the vocabulary CNS's use when communicating with people with cancer. The objectives of the study are to:

- Examine whether CNS's are aware of the vocabulary they use

- Explore to what extent CNS's regard vocabulary as important

- Identify how CNS's have and continue to formulate their vocabulary

- Explore their perceptions of whether their vocabulary has changed over time

CHAPTER 3

Research Design

3.1 Theoretical basis and methods

3.2 Research design

3.3 Sample, participants and setting

3.4 Measures, data collection techniques and study instruments

3.5 Data reduction and analysis

3.6 Quality assurance and ethical issues

3.1 Theoretical basis and methods

Research Paradigm

A paradigm is a pattern, model or way of viewing natural phenomena from a real world perspective used to guide inquiry (Polit and Beck, 2010). Commentators including Holloway and Wheeler (2010) suggest there are two paradigms that can be applied to health research; positivist and naturalistic. This study is under pinned by the naturalistic philosophical paradigm. This paradigm is concerned with subjective human experiences and the contextualised interpretation of these. In the positivist paradigm reality is known and fixed (Polit and Beck, 2010). In the naturalistic paradigm reality is not fixed, realty is constructed by studying the experiences of people within a setting and context (Grove, Burns and Gray, 2013). This study is concerned with constructing the reality of factors that influence the vocabulary used by individual CNS's within the context of the CNS role, the setting of a DGH and communication with people with cancer for which the naturalistic paradigm is appropriate.

Research approach

Research underpinned by the naturalistic paradigm is explored using a qualitative approach (Steen and Roberts, 2011). For Polit and Beck (2010) this inductive approach facilitates the understanding and meaning of 'lived experiences' through the subjective and narrative gathering of themes, concepts and ideas. Naturalistic qualitative research does not begin with a defined concept or hypothesis, concepts emerge out of the exploration of the phenomena under study, the findings generated and the interpretation of these (Grove, Burns and Gray, 2013).

Within the scope of the literature review undertaken it would appear the proposed topic has not been researched before. In these circumstances Meadows (2003a) suggest a qualitative approach is required to gain in-depth insight into the phenomena. The majority of studies in the literature review use a qualitative approach.

3.2 Research design

Research methodology

Grove, Burns and Gray (2013) cite five approaches to qualitative research; grounded theory, ethnographic, exploratory-descriptive, historical and phenomenological. Grounded theory explores social interactions and people's actions and behaviours within these. The social interactions of CNS's are not being examined in this study. Ethnography is concerned with studying cultures and attempting to understand the world view of those being studied. Whilst it could be argued CNS's may have a culture the study is not seeking to understand their world view. Exploratory-descriptive research seeks to understand the needs and views of a particular group. The aim is to create a specific intervention or program out of the findings which this study is not aiming to do. The historic approach examines past events and the context in which they occurred. Whilst this study is looking at influences on CNS vocabulary which may be historic, it is influences and not events that are under scrutiny. Phenomenology is concerned with the lived experiences of people. This study is seeking to understand the lived experiences of CNS's use of and choice of vocabulary in their communications with people with cancer and the influences upon their vocabulary. Phenomenology has been chosen as the method for this study.

Grove, Burns and Gray (2013) describe two approaches to phenomenology, Husserlian and Heideggerian named after the philosophers Husserl and Heidegger. In Husserlian phenomenology the researcher examines the world view of participants having set aside any prior assumptions or self beliefs on the topic under scrutiny a process known as 'bracketing'. Heideggerian phenomenology does not consider 'bracketing' is possible, arguing the researcher's thought processes are shaped by their own experiences and perceptions which will influence the interpretation of the data. The researcher is a nurse, has been a seconded CNS and during the course of this study has become a CNS. The study originated out of an experience involving the researcher. For the reasons highlighted it was decided 'bracketing' would not be possible and so this study has adopted the Heideggerian approach.

In Heideggarian phenomenology Grove, Burns and Gray (2013) described how people and their experiences are 'situated' within a specific time and context and how time and context are important to understand and make sense of people' experiences. Heidegger's 'being-in-the-world', the notion that a relationship exists between a person and the world and time they inhabit is central to Heideggarian phenomenology (Holloway and Wheeler (2010). The CNS's in this study are 'situated' by their role as a CNS, the DGH where they practice, caring for people with cancer and cancer being a priority of the DH. These 'situations' define the CNS's 'being-in-the-world' and it could be argued will have an effect upon the CNS's lived experiences and factors that influence their vocabulary.

Research Method

To obtain data on lived experiences the research must involve interaction with participants. Grove, Burns and Gray (2013) suggest the following methods; observation, focus groups and interviews. Polit and Beck (2010) describe interviews as a 'self-reporting' method as participants report on what the phenomena means to their self. As this study seeks to explore the self-reports of CNS's lived experiences, individual interviews appear appropriate. Observation would have required the researcher to observe the conversations between CNS's and people with cancer. This would not have provided data on the vocabulary the CNS's used but not on the influences on the vocabulary. Focus groups do not capture detailed individual experiences, the group environment can restrict participant contribution and participant views can be influenced by others. For the reasons stated these methods were not chosen.

Three types of interview exist; structured, semi-structured and unstructured. Structured interviews use a pre determined question format which Parahoo (2006) suggests is akin to the quantitative format and unsuited to phenomenological studies. In contrast unstructured interviews use no pre-determined questions making the interview difficult to manage (Parahoo, 2006). Between the two is the semi-structured interview which uses a guide to introduce themes within the study to steer the interview. According to Holloway and Wheeler (2010) this interview format provides a degree of focus whilst remaining flexible and responsive to participant feedback. This format minimises what Holloway and Wheeler (2010) term data 'dross rate', being data which is not relevant, as the interviewer is guiding the interview. For these reasons the semi-structured interview format using an interview guide has been chosen for this study despite the limitations of following a guide

which can inhibit free expression by the participant and become the focus of the researcher.

An interview guide outlining a rough structure for the interview and some questions on the areas to be explored was developed (appendix 2). The guide was flexible allowing other questions to be asked based on the CNS's responses. Whitting (2008) recommends using probing questions to draw out information from the participant. The same opening question was used from which a variety of probing questions and discussion routes developed. As common themes emerged, common probing questions were used across the interviews. Individual themes were explored using bespoke probing questions.

Polit and Beck (2010) advocate the need for consistency between the research approach, methodology and method. There is consistency in this study. The naturalistic approach examines human experiences; within this approach phenomenology examines lived experiences for which semi-structured interviews are a recognised method to collect data.

3.3 Sample, participants and setting

<u>**Sample and setting**</u>

According to Polit and Beck (2010) qualitative research invariably uses samples that are small, non-random and represent the population being studied. For interviews Kvale (1996) suggests six to eight participants is appropriate as qualitative research findings are not generalised. There are different types of sampling; convenience, snowball, theoretical and purposive. This study will use

purposive sampling. In purposive sampling the researcher chooses the population that will best provide information and data on the subject matter being studied.

As the study concerns the vocabulary of CNS's at a DGH then the CNS's at that DGH are the population that will provide the best information and data. Polit and Beck (2010) describe how in phenomenological studies researchers need to select people who have experienced and lived the phenomena which thereby necessitate a judgmental and purposive selection approach. Within purposive sampling Polit and Beck (2010) describe four different types: maximum variation, extreme, criterion and typical. Typical sampling involves selecting a population who represent what is average or typical. The population of CNS's at the DGH can be regarded as typical.

People with cancer encounter multiple specialities during and after treatment. A population covering all specialities could produce a sample size outside the scope of qualitative research and may not achieve the degree of homogeneity as CNS's. A 'DGH' has been chosen as the CNS's job description and role are very similar. A sample of CNS's from different environments e.g. tertiary centres, hospice and charities where the roles may differ could introduce too many variables.

At the DGH where the study was conducted the CNS population of 14 comprises two lung, one gynaecology, one urology, three breast, two haematology, three colorectal, one dermatology and one acute oncology. As the criterion is CNS's at the DHG the total population was included in the sample size. Before this study commenced I worked with the breast and gynaecology CNS's on a four month secondment as a CNS. Whitting (2008) suggests it is difficult to interview work colleagues where there are established relationships. It could be argued my

experience in the role could introduce bias. However four months saw me operating at a basic level in the role not fostering established relationships and not gaining depth of experience that could bias the interviews therefore the breast and gynaecology CNS's are included in the sample.

NHS National Patient Safety Agency (NHS NPSA) (2012) state participants should not be given study information to read in isolation. NHS NPSA (2012) suggests informed consent is best achieved by the researcher going through information with participants. Following the suggestion of the NHS NPSA I briefly introduced the study to eight of the 14 CNS's attending one of their regular quarterly meetings in April 2013. In the following week I briefly saw all 14 CNS's reiterating to those who had been at the meeting and introducing to those that had not the purpose and nature of the study. After assuring the CNS's that their participation was voluntary and all information would be treated in confidence I left with them an invitation to participate letter (IPL) appendix 3, a participant information sheet (PIS) appendix 4 and a consent form, appendix 5. To keep to the study timetable and not leave the invitation with an open ended response timeframe the CNS's were given a response time of seven days.

Research is best conducted in an environment that participants are familiar with and spend the majority of their time according to Mapp (2008). The DGH chosen for the study is where the researcher and participants work and is therefore familiar and where the CNS's spend their working time. However, Holloway and Wheeler (2010) advise against conducting research in the workplace with people familiar to the researcher as the participants may feel an obligation to participate. Whilst this point is acknowledged the scope and timescale of this study are not

conducive to conducting the research in another DGH and the CNS's were fully aware participation was voluntary. To meet Whitting's (2008) suggestion that interviews should be conducted in a comfortable environment formal meeting rooms which may have been impersonal and alien to the CNS's were not used. I used the patient consultation room within the breast care unit as it has an informal and relaxed atmosphere. The Breast CNS's indicated they had no issues with using this room for an interview if selected.

3.4 Measures, data collection techniques and study instruments

Pilot study

Silverman (2010) suggests a pilot or dry run of an interview is sensible and deemed a feature of good research. However, for Holloway and Wheeler (2010) a pilot study is not in keeping with the developmental nature of qualitative research. Silverman (2010) quotes a research student recounting that a pilot helped them practice their interviewing technique. As I felt comfortable with interviewing and I did not want a pilot interview to influence or prejudice my thinking and approach to the actual interviews I did not conduct a pilot.

Data collection

Of the 14 CNS's invited to take part a response rate of 43-57% would be needed to generate the desired six to eight interviews. The qualitative studies considered in the literature review were unhelpful in corroborating whether this response rate was realistic or not. A contingency plan to manage a response rate greater than 57% was established. Each respondent name would be written on a 5cm by 2cm white piece of paper, folded and placed into a Scrabble tile bag. The

lead CNS would select the participants by drawing out eight pieces of paper. Details of the process were given in the IPL.

The contingency plan and contingency selection letter (appendix 6) was not needed as eight CNS's expressed an interest in participating. All eight were sent a confirmation letter of participation offering dates and times for an interview (appendix 7). A response date was indicated in the letter for the reasons stated earlier. Six participants responded by this date and interviews were arranged. The two non-responders were followed up, they still wished to take part and interviews were arranged.

At the interview I supplied the CNS with a hot drink and cake whilst we briefly talked about how their day had been, a legitimate way to establish a positive social environment according to Grove, Burns and Gray (2013). This was welcomed by the CNS and helped create a relaxed atmosphere before moving into the formal process of the interview. The CNS's were all keen to be interviewed expressing interest in the study topic and subsequent findings. This meant that although some came a little nervous of what they were going to be asked, they all engaged with the process and topic.

In the proposal for the study it was anticipated the interviews would last 60 minutes as stated in the IPL. In reality the interviews varied in length from 23 – 42 minutes, the average being 32 minutes. This is at the lower end of the length of interviews as quoted by Steen and Roberts (2011) and Parahoo (2006) of 30 – 120 minutes. At an average of 32 minutes the exhaustion point fell short of the 90 minutes suggested by Meadows (2003b). For Steen and Roberts (2011) the

interview should end when no new information is being revealed or the interview becomes repetitive. In all the interviews I was satisfied the CNS had offered all the information they could and the themes on the interview guide had been explored adequately.

The interviews were digitally recorded as recommended by Steen and Roberts (2011). Digital recoding leaves the interviewer free to concentrate on the interview and interviewee according to Kvale (1996) and has the advantage over written recordings of capturing participant intonation, tone, volume and pauses which can add depth and meaning to what is being said. The CNS's were advised of the recoding method in the PIS. After reminding the CNS of the digital recording and ensuring they were happy with this the device was positioned on a table between them and me. To maintain anonymity the CNS's name was not used during the interview. The technique of 'remembering' suggested by Kvale (1996) was used after each interview to record details of any non-verbal language and any atmosphere created that was not captured on the recording.

3.5 Data reduction and analysis

Data analysis

For Polit and Beck (2010) the purpose of analysis is to organise, structure and draw meaning from the collected data. As the data is voluminous in nature according to Denicolo and Becker (2012), an organised, consistent and systematic, approach is required from the start. Polit and Beck (2010) state analysis of qualitative date is challenging as there are no agreed rules of analysis, the volume of work is huge, the analysis requires powers of inductive insight and reasoning and the data must be reduced to a reportable size and format.

There are a number of frameworks for analysing qualitative data detailed in the literature. For phenomenological studies Polit and Beck (2010) suggest frameworks by Colaizzi, Giorgi and Van Kaam. However specifically for Heidegerrian phenomenology Steen and Roberts (2011) suggest the frameworks of Diekelmann, Allen and Tanner and Cohen, Kahn and Steeves. Cohen, Kahn and Steeves (2000) framework has been chosen as the authors are researchers who have undertaken phenomenological studies and have written a research guide for nurse researchers.

For Cohen, Kahn and Steeves (2000) the data analysis process begins not when the data is all collected but runs concurrent with the data being collected, an approach supported by Di-Cicco-Bloom and Crabtree (2006) and Parahoo (2006). This allows the researcher to reflect on what has been said by participants and begin to determine meanings. After the first two interviews this process came naturally. It would be difficult to conduct the interviews without starting to reflect on what had already been said and start to construct meaning especially when some of the themes began to be reported by several CNS's. The challenge was applying reflexivity to keep this knowledge parallel to the interviews to avoid skewing the interviews to what had been gleaned rather than conducting them as planned following the topic guide to ensure the collection process was consistent and remained valid.

As Whitting (2008) suggests, the process of verbatim transcription was challenging and time consuming as highlighted by Polit and Beck (2010). To manage the process, interviews were transcribed in parallel with conducting the interviews. Spencer, Ritchie and O'Connor's (2003) calculated that one hour's tape

taking six to eight hours to transcribe which proved correct. The 235 minutes of conversation took approximately 24 hours to transcribe.

After the recordings were transcribed I began Cohen, Kahn and Steeves's (2000) next stage which involved immersing myself in the data by reading and re-reading the transcripts. This allowed me to get an overview of the data and to build on the themes that I had seen emerging from the reflexive process begun whilst conducting the interviews. The next stage in Cohen, Kahn and Steeves's (2000) framework is 'data reduction' where the researcher decides what data is relevant setting aside what is not. The majority of the data is rich and directly relevant resulting in a small amount being discarded.

The remaining data was subjected to thematic analysis with each line of data being analysed. Significant statements were highlighted using colour, a suggestion made by Parahoo (2006), via highlighter pens, the same colour being used for statements on a common theme. Quotable data that could be used to illustrate particular points was underlined in pen with 'QUOTE' written in the margin. Notes were written in the margin to highlight points of interest and cross reference common themes between transcripts. All of these annotations some as suggested by Cohen, Kahn and Steeves (2000) were done is a clear, systematic, organised way to ensure clarity of thought process and allow cross referencing at the end of the process.

The next stage in Cohen, Kahn and Steeves (2000) framework is to group together text where there are similar themes. I adapted Krueger and Casey's (2000) 'long table approach'. As the transcripts were on computer the cut and paste

function was used to group the data by themes in a separate document. Each themed section was labelled with the interview number to facilitate cross referencing. This proved to be an efficient way of grouping the data together.

Following this exercise 26 influences on CNS's vocabulary were identified. From this four umbrella themes readily emerged with the 26 influences being appropriately allocated to one of them. The interpretation and documenting of the data to produce a narrative text is the next stage of Cohen, Kahn and Steeves (2000) framework. This involved an iterative process of writing and rewriting to produce an accurate, coherent and fluid record of and understanding of the CNS's experience of the factors that have influenced the vocabulary they use when dealing with people with cancer.

Cohen, Kahn and Steeves (2000) appear to suggest that the themes arising from participant data can be verified with them but do not state how this should be done. For the purposes of verifying the data with participants, this study adopted the approach of Parahoo (2006) and Kvale (1996) and sent the draft report of the findings to the CNS's for their comment and validation. Each CNS was sent a personalised e-mail with an electronic copy of the file attached. They were asked to review the text and provide comment within a two week timescale. Four CNS's responded with favourable comments, they made no requests to change the findings.

3.6 Quality assurance and ethical issues

Credibility and trustworthiness

Polit and Beck (2010) describe the debates and arguments that exist around the issue of demonstrating the integrity of qualitative data. For Polit and Beck the outcome is a plethora of terms however no agreed criteria. Despite this Polit and Beck (2010) and Streubert and Carpenter (2011) cite the framework of Lincoln and Guba (1994) as the 'gold standard'. The framework uses five criteria to assess qualitative rigour; credibility, dependability, confirmability, transferability and authenticity. For Streubert and Carpenter (2011) the aim of rigour in qualitative research is to represent participants' experiences accurately and for Holloway and Wheeler (2010) the aim is to demonstrate thoroughness and competence.

For Polit and Beck (2010) credibility is concerned with the degree of confidence regarding the truthfulness of the data and the degree to which the findings represent participant experiences. 'Member checking' as suggested by Streubert and Carpenter (2011) was used to check whether the analysis reflected the CNS's experiences. CNS's were sent a draft of the analysis and invited to comment. Polit and Beck (2010) suggest 'peer debriefing' as a method of improving trustworthiness. A limited amount of 'peer debriefing' was done with the study's supervisor. Parahoo (2006) suggests all or part of the transcripts should be read by other researchers to compare perceptions and thoughts. This method will not be adopted as Streubert and Carpenter (2011) suggest it can lead to confusion as each person will have their own insight based on different backgrounds and experience.

Dependability concerns the reliability or stability of the data and the degree to which if the study was replicated the results would be comparable (Polit and Beck, 2010). Streubert and Carpenter (2011) and Polit and Beck (2010) agree dependability cannot be attained without credibility being in evidence. Authors including Holloway and Wheeler (2006) and Steen and Roberts (2011) agree that an audit trail detailing each stage of the process is required to demonstrate dependability. Accordingly an audit trail has been kept for each part of this study.

Confirmability according to Steen and Roberts (2011) is the degree to which the findings are an accurate and faithful reflection of the information provided by participants and not a reflection of the researcher's perceptions, biases and perspectives. To evidence confirmability this study has followed the advice of Holloway and Wheeler (2010) and kept an audit trail of the source of the data and a record of how the conclusions were derived. The findings were subjected to 'member checking' by participants.

For Silverman (2010) transferability concerns the degree to which the findings can be transferred to other groups or settings. Steen and Roberts (2011) argue the low numbers of participants used in qualitative research means the findings cannot be generalised. Lewis and Ritchie (2003) suggest qualitative data can be generalised to the population from which the sample was drawn. For Streubert and Carpenter (2011) the decision as to whether findings can be generalised lies with the reader or users of the findings. It is possible that the findings could have relevance to CNS's in other DGH's however generalisations could not be made from such a small sample.

The fifth element of Lincoln and Guba's framework is authenticity. Polit and Beck (2010) describe authenticity as the degree to which the researcher conveys the reality of participants lived experience by conveying a sense of participant's feelings, language and mood. This has been achieved through the extensive use of quotes from the rich data collected which enlivens the findings.

For Parahoo (2006) credibility and trustworthiness is underpinned by the researcher practicing reflexivity and reflection. This has involved me being aware of and documenting my assumptions, preconceptions, biases and own experiences of the phenomena to ensure I do not pre-judge the data collection, analysis and interpretation. In view of this study adopting the Heideggerian phenomenological approach this is especially important.

Ethical Considerations & Research Governance

To maintain participant rights and protect them from harm, distress, breaches of confidentiality and loss of anonymity all research must comply with and uphold the ethical principles of autonomy, beneficence, non-malificence and justice. All DH research must comply with the DH Research Governance Framework (RGF) (2005) which sets out rigorous standards, processes and procedures designed to maintain public and participant confidence in and the benefits of health research.

Ethical approval for this study was submitted to the UC Research Ethics Committee (REC) in March 2013 and to the DGH Research Manager in April 2013. Both parties gave approval to proceed (appendix 8 and 9 respectively). A member of the university REC advised the study did not require submission to the DH for approval. The following review incorporates principles of good governance for

healthcare research as detailed in the DHRGF (2005).

Avoidance of harm and distress

Maintaining and protecting participant wellbeing, dignity, safety and rights are of prime concern in research studies (DH, 2005). The subject matter of the study was not expected to cause CNS's harm however measures were put in place to help minimise the risk of harm being caused. CNS's were introduced to the study at a quarterly meeting and or individual meetings. No pressure or coercion to take part took place. Each CNS was given an IPL, PIS and consent form providing further details of the study. The CNS's were told verbally and in writing that their participation was voluntary, that they could withdraw at any time and that informed written consent would be obtained. CNS's were made aware verbally and in writing that the lead CNS at the DGH was available for them to contact with any concerns or issues regarding any stage or aspect of the recruitment and interview process.

The interviews were conducted in the breast care clinic with a drink and cake provided. General conversation took place prior to starting the interview to help relax the CNS and build rapport. Two CNS's admitted to feeling nervous before the interview, they were asked if they wished to proceed and reassured they could withdraw at any time. They were happy to continue and the interviews were completed. Parahoo (2006) suggests the interviewer can cause harm by their behaviour and demeanour and before, during and after the interview. The researcher bound by the Nursing and Midwifery Council (NMC) Code (2008) maintained professional standards and there were no reports from CNS's of any issues with my behaviour or demeanour.

Potential benefits for participants

CNS's should feel proud of the contribution they have made via the study to the body of knowledge concerning cancer communications. In discussing and reflecting on their vocabulary and factors influencing this, the CNS may change or adapt their vocabulary for the benefit of patients. The CNS's will be able to record their participation as NMC continuous professional development.

Health and safety issues for researchers

Researchers have a duty to ensure participants receive 'appropriate care' during the research process (DH, 2005). The health, safety and well-being of the CNS's was maintained as the interview room adhered to the policies of the DGH in line with the Health and Safety at Work Act 1974. A low table was used for the hot drinks and cake.

Participant recruitment, criteria, reimbursement and relationship

All 14 CNS's were invited to take part. The process for managing a response rate greater than 57% was clearly detailed in the IPL. This process was open and ethical providing a practical solution to manage the study which in the event was not required. Recruitment was entirely voluntary with no incentive offered to elicit a response. The offer of a hot drink and cake was a goodwill gesture for the CNS at the end of a busy working day and should not be considered an incentive or bribe to participate.   There were no expenses to be reimbursed as the interviews took place at the CNS's workplace.

The researcher worked with the breast and gynaecology CNS's on a short term secondment. 'Established relationships' were not fostered therefore thereby

minimising issues concerning any obligation to participate or coercion by the researcher. At the time of conducting the study I was a grade lower than the CNS's and therefore subordinate to them. The study was being carried out as part of my Masters programme. My grade does not require a Masters when CNS's are being encouraged to obtain this qualification. These issues could have been a potential limitation on CNS's willingness to participate and speak however this was not experienced in practice. The IPS made CNS's aware my studying was for personal development and assured CNS's that their expert input was valued.

Informed consent and confidentiality

Informed voluntary consent is central to the ethics of research (DH, 2005). For Holloway and Wheeler (2010) informed consent is inextricably linked to autonomy requiring participation to be voluntary and for participants to be aware of the benefits and risks of taking part. The IPL and PIS clearly state the risks and benefits of participation, that consent will be gained and that data will be anonymous. All the CNS's were deemed to have capacity to consent. The information CNS's were given provided sufficient detail to make an informed choice. CNS's interested in taking part were asked to complete a consent form. This form was returned with their response slip but not countersigned by the researcher until the CNS had reconfirmed their willingness to participate at the interview. The IPL stated CNS's can withdraw their consent prior to any dissemination or publication of the findings. The consent forms are kept in a double locked facility.

Management of data

To comply with the Data Protection Act 1998 this report does not include any information that could be used to identify participating CNS's. The digital interview recordings do not include any names. Some CNS's referenced their speciality in the interview which could help identify them. This risk has been minimised by the speciality not being referenced in the quotes used in the findings and the recordings being password protected on my computer. Participant recordings were identified by a number allocated to them. CNS names and allocated numbers are stored in the same facility as the consent forms. The transcriptions are stored in a separate double locked facility. All materials will be kept for two years after the research has been conducted to evidence credibility and trustworthiness if required, after which time paper records will be destroyed via the DGH confidential waste system and the file containing the recordings will be deleted from my computer. Details of these arrangements designed to maintain the confidentiality and anonymity of the CNS's are detailed in the IPL and PIS.

Vulnerable groups

The CNS's at the DGH are not considered to be a vulnerable group. They are all competent HP's with capacity to make an informed choice to participate and withdraw at any time. The interview may cause the CNS to reflect on their practice and personal experiences, the DGH lead CNS was available to discuss any issues that arose.

CHAPTER 4

Findings

4. Findings

This chapter presents the research findings. The aim is to understand factors that influence the vocabulary CNS's use when communicating with people with cancer. Having subjected the data to thematic analysis, four broad themes representing four key factors that influence CNS's vocabulary emerged; people with cancer, personal, process and publicity. Each of the four themes encompasses sub themes.

The theme 'people with cancer' includes the vocabulary of people with cancer, non-verbal language, narrative and the influence of relatives. The 'personal experience' of the CNS includes level of experience in the role, knowledge of speciality, confidence, personal experience of cancer, reflection and listening and learning. The third broad theme 'process' includes themes concerning consultants, stage of the patient journey, training courses, cancer type, environment, terminology, policy and team working. The fourth main theme 'publicity' includes the influence of media awareness, the internet and literature.

4.1 People with cancer

4.1.1 Vocabulary

All the CNS's cited the vocabulary the person used as an influence on what vocabulary they then used. CNS's elicit the person's vocabulary via open questions,

…when I first see a patient I ask them if they have got any questions and see what terms they use and use that back… interviewee (IV) 1

However almost all of the CNS's qualified this by saying they would only use the person's vocabulary if they felt the person understood what they were using,

…stick with more technical/medical terms…so long as I know what they understand by the term… IV5

…I'll listen to their language and go back…and say what do you understand a [term] could be… IV4

The CNS would check any misunderstandings and dispel any misconceptions of a term or situation especially the use of 'cancer',

...if they don't say tumour or cancer often they haven't understood that it's a cancer we're talking about… IV4

…if they weren't saying cancer…I would use the word cancer I need to know that they fully understand what we're talking about… IV8

The vocabulary people use can also give the CNS an indication of their level of vocabulary and understanding,

…it's the way they phrase their questions to me…when they say…I pooh I think OK were talking at this level or if someone…says when I'm defecating I think OK we're in that level… IV2

Having established what vocabulary the person uses IV7 noted the challenge is

…remembering then for next time that you meet that that is the way they want that information delivered…

4.1.2 Non-verbal language

The non-verbal language people with cancer exhibited was an influence on the vocabulary five CNS's used.

…non-verbal aswell…sometimes you know they are so shocked you can see it

before you even open your mouth… IV1

Three CNS's reported they know immediately if the person is uncomfortable with the vocabulary they have used by their non-verbal reaction,

…if it's a word they don't like you can usually see it in their expression you know if you use the wrong word by how they react… IV8

The CNS's respond by,

…it's almost a case of pulling back and using another word maybe… IV5

…you don't use it again…you refine what you say over and over again …let them lead…see how their body language is, how they have reacted to what has been said… IV3

…young patients who are very angry about being brought into our sort of clinic…they'll often sit with crossed arms and lean back and just frown the whole way through why am I here, I don't want to know, I don't want you to do any of this…being quite aggressive in their manner…so there's a lot of body language in this environment… IV4

4.1.3 Narratives

Patient narratives had been an influence on the vocabulary used by two CNS's and on them as a person.

…some of my patients have…had a major influence on how I do the job…patient narratives are fantastic…hearing their stories they can really hit you, you think wow I didn't realise that … IV7

…the way they respond that's fed me…made me the person I am…what you get

back from them you can put into someone else… IV8

4.1.4. Relatives

Relatives were reported as an influence by three CNS's.

…some…relatives are needier than the patients so I'll take into account what I say for them too… IV3

…I find that the relative may ask more questions than the patient…I am aware of the patient as the relative is asking and if they're getting uncomfortable I'll say that's enough… IV2

4.2 Personal

4.2.1. Experience

Experience in the role was cited by five CNS's as a factor that influenced their vocabulary. Three CNS's discussed how they felt when they started the role.

…it was sometimes difficult to be as direct…I would follow more what they said to me…broach things more carefully… IV1

…absolutely terrified of speaking to them because they had cancer… IV2

…I was always very serious …you're more worried about what you're saying than listening to the person… IV3

All five CNS's reported that experience developed their vocabulary and the way they speak to and deal with people with cancer.

…I'm less afraid of how they may respond now so if they get upset I'm happy with dealing with that… IV1

…I used to be a lot more sympathetic…now I'm much more here are the facts and where we go from here and what do we do, I seem to have a much better

effect they don't seem to go away crying sometimes they go away laughing...
IV5

...when you start to relax...you're not so worked up about getting it right...you have a more natural conversation...you might have a laugh and a joke... IV3
(who began very serious)

When asked how important they felt experience was in terms of the vocabulary they use all five said it was an important factor.

Massively... the most important thing when it comes to communication...is experience... IV2

...I would have to say that was experience over the years... IV5 when asked what was the most important influence on their vocabulary

4.2.2. Knowledge of speciality

In discussing experience, four of the five CNS's cited knowledge of their speciality as a factor integral to in developing experience.

...you need...the knowledge of what you're talking about because...if you're not quite sure what you're talking about again you're scared of what they may say... IV1

...knowing your stuff so if you haven't got the answers you're able to signpost them to a way they can get the answers... IV2

4.2.3 Confidence

Confidence was a factor that influenced six of the eight CNS's vocabulary. Four of the six were the CNS's who cited experience and speciality knowledge as factors influencing their vocabulary who in turn commented that these factors

developed their confidence,

*…as you get older you get a bit more confidence…more confidence in your speciality…and the confidence comes with experience…*IV8

IV4 summed up the beneficial outcome of increased confidence on interactions with people with cancer,

…confidence changes the focus of conversation from factual and practical to include psychosocial and emotional…

CNS's in the role for a number of years were asked how long it took them to feel confident the consensus view appeared to be,

…it probably takes a good two to three years to get there… IV1

Two CNS's newer to the role offered insights into their confidence and the effect upon their interactions with people with cancer. IV4 acknowledged lack of confidence had been a limitation on the vocabulary they used and conversation they had with people with cancer,

…I probably kept a bit back in case they asked me a question I didn't know the answer to…

However with increased confidence the CNS found,

…the time I spend with people has probably increased, I'd say I spent 20 mins perhaps half an hour with a new patient and now I can spend an hour or more quite comfortably…I think the quality of time they get with me is better…now I'm quite confident to sit and answer any questions they've got…

On starting the CNS role the other CNS found they,

…went rock bottom I felt no confidence at all and still now it is at a point where

50% of the time you feel super confident and then 50% of the time you question…I think when your confidence goes you can become quite closed and defensive in your communication you have not got the confidence to delve in and speak whereas if you are more confident then you tackle wider issues…if you are not confident you do not go there … IV6

4.2.4. Cancer experience

Three CNS's revealed how a personal experience of cancer influenced the way they empathised with and conversed with people with cancer.

…it's easier because I think you have that understanding cos you've been there that you understand… IV3

For IV4 a cancer experience with a family member made them want to,

…make sure that everyone…feels supported and that I get to meet them and engage with them and not just give them my number and send them on their way…I always think if this was my mum or my gran how would I like them to be spoken to …

4.2.5. Reflection

Reflection on conversations, highlighted by four CNS's as an influencing factor, has resulted in CNS's saying things differently.

…I wrote a reflective piece on me using technical terms when I should not have, should have kept a basic language… IV5

…it's about reflecting and thinking well how could I have done that a little bit better… IV6

4.2.6. Listening and learning

For all but one CNS listening to and leaning from others was a factor that influenced their vocabulary and communications. For IV2 the multi disciplinary team (MDT) approach to cancer care means,

…you can say well I really didn't like the way they said that you make a mental note I'll never say it in that way but someone else might say something and you think that's a really good way of explaining things and then you run with that…

For IV4 previous ward experience influenced their communication,

…I think I've learnt how not to speak to people probably…and some nice ways to talk to people…so I think that swayed my communication before I got here…

Although the CNS's listened and learned from others,

…at the end of the day you have to find what's suitable for you…because ultimately you're not that person… IV3

4.3. Process

4.3.1. Consultants

The vocabulary used by consultants was highlighted by three CNS's as a factor influencing the vocabulary they used.

…the vocabulary our consultants use is very different between the two…one will talk about a shadow or a mass…the other will talk quite openly about cancer… my vocabulary is based on which consultant the patient sees…what I have to say depends on what the consultant has said to them … IV4

Consultants are not consistent in their use of the word cancer.

…they are a bit inconsistent…the more intelligent understanding patients they may use the word cancer then the ones that look a bit less academic they assume they don't understand and they try and be gentler and don't use the word cancer and they are the ones that do not necessarily understand where we are coming from… IV5

…other peoples vocabulary has altered making it easier from our point of view …there is less nonsense talked…everybody's understanding of breaking bad news is a little better they either did it very harshly and very badly or they didn't give them the right information and I used to have to pick up the pieces but that's not the case now we work far more closely as a team the specialist nurse and the consultant we know how each other speaks … IV7

The MDT approach to cancer care means CNS's often sit in on consultations with people with cancer.

…I try and sit in with the consultant first so I've got a bit of a feel of how the

consultation has gone and how they have responded to the things he's said so

that I can direct the way I talk to them…" however, *"…one of our consultants he*

doesn't call us until he's seen the patient and so then you're a bit in the dark and

you have to start from a different playing field…do you understand what's been

said, can you tell me what's been said and go around it so I understand what

their understanding is before I wade in… IV4

A challenge appeared to be,

…translating the doctor's words into understandable language for the patients…

IV4

A CNS was encouraged that,

…younger doctors are a bit better…the newer ones…that is probably their

training I think they have been told to make sure the patient understands… IV5

4.3.2 Stage of journey

A theme arising from the data was the influence the stage in the cancer

journey had on the choice of vocabulary used in communication.

…I think it depends where you are with the patient… IV1

Where there is a degree of suspicion pre-diagnosis that the person may have a

cancer, all the CNS's reported using words or phrases that convey this suspicion

without using the word cancer. These include, 'suspicious', 'abnormality', 'tumour',

'mass', 'growth' and 'we're slightly concerned about this' or 'we're slightly worried

about this',

…this does look…suspicious just to give them that idea of oh yeh… this is

something serious now… IV3

However four of the CNS's stated that if the person with cancer used the word

cancer pre-diagnosis they would use cancer back,

…we've not got histological proof…so we don't come out straight and say this is a cancer but if the patient then says could this be a cancer then I confirm yes this could be a cancer… IV7

All eight CNS's stated that they use the word cancer as soon as possible in their communications and at all times once a diagnosis is confirmed. One CNS reported that the nature of the conversation the person wants or needs to have can be an influence on what is said,

…it's different cos I'm very much focusing on diagnosis and the information we need to give around that, it might be slightly different if someone comes with concerns and they're upset it may be more of an emotional chat… IV5

One CNS is involved with people after they have been diagnosed and are listed for surgery. Meeting the person at this stage the CNS uses particular words,

…this is a bit of a rollercoaster for you…it's a bit of a treadmill that you are on…there are different hurdles… IV8

4.3.3 Courses / training

The CNS's were asked whether training courses had been an influence on their vocabulary. CNS's who had been in the role for some time reported a similar view on the role of training and courses,

…I think a lot of the time they're telling what you already know but they're also reminding you of all the ways you fall back into…I guess all communication courses I have benefited from…it just highlights to me and reminds me the best way of doing things… IV1

Five CNS's stated the Advanced Communication Skills Training (ACST) had

been an influence especially on CNS's newer to role.

…we have to do the ACST and I learnt a phenomenal amount and the main thing I learnt from it was that the most effective communicator actually says very little… IV2

…[recalled using an analogy to describe treatment]…attending the ACST course it questioned if that was quite an appropriate way of talking about something… IV6

All CNS's indicated that training provided them with a foundation however it was experience in the role that enabled them to develop their style of communication and vocabulary,

…it doesn't matter what training you have been on…its like driving a car you can have all the lessons but its not until you have been doing it for a bit that you know where your going and I think that's what its needs really is experience… IV5

4.3.4 Type of cancer

Four CNS's reported that the type of cancer they specialised in enabled them to be more positive in their communications and use of vocabulary.

…in [specialist] cancer…cos its external rather than internal cancer and we've got treatments perhaps more than other cancers…I think other cancers have this death sentence maybe…but I think perhaps it's a little less in [specialist] so we can be a little more positive… IV3

…I am quite positive about what I say in general…in [specialist] about 50% will survive…much better survival rate than other cancers so I'm pretty confident when I'm talking to them… IV5

4.3.5 Environment

Environment was mentioned by three CNS's. Two CNS's reported that people with cancer had reacted negatively to general conversation they had engaged in outside of the formal appointment.

…people come back to me when I've been trying to be more general…so as I was walking someone to a room and just said oh how are you, they've turned round and said how do you expect me to be I've just been diagnosed with cancer... IV1

IV4 mentioned the effect of the ward environment on the person with cancer and what the CNS could say,

…different when I see people on the ward because I don't think anyone is quite the same when they're in hospital so its really difficult to get a clear picture of them often when you see them on the ward for their initial appointment and then they come back to clinic they seem like a different person…they come back more forthright and they have their own opinions…when you go into meet someone for the first time on the ward often they are on their own…I always feel that they are quite vulnerable…they are on their own and they're usually not feeling well…

4.3.6 Explain terminology

The use of terminology with people with cancer was commented upon by five CNS's. The CNS's qualify their use of terminology by ensuring the person understands what is being meant or the term being explained in laymen language.

…I think the majority of women will accept the terminology that we use so long as it's understandable to them… IV1

…I'll always use the technical term and I tend to give an explanation… IV3

IV5 uses the word cancer and,

…everything else is just layman's speak…wherever they are in the academic scale they all get the same…

Sometimes technical or medical terminology is used,

…give them the technical information because that is what they get in the letter but then I'll give a layman's equivalent… IV6

...they deserve to understand the technical terms to be told what the technical terminology is… IV7

4.3.7 Policy

CNS's were asked if terminology used in policy documents had been subsumed into their vocabulary. The consensus view was that policy had not altered the vocabulary they used.

…jargon isn't necessarily patient friendly…I don't want to sound like the adverts on telly or sound like I'm reading it from a book… IV4

…lots of those words rub me up the wrong way I'm not a great lover of all the new blurb, I'm not sure that its helpful… a relationship is between two people and its got to feel right to impose something from outside is not necessarily right for that individual patient…I think if you just use the terms then you're missing the point really… IV7

4.3.8 Team working

Working as part of a team of CNS's was highlighted by one CNS as an influence on the vocabulary and communications they had with people with cancer,

…there are a lot of us in the department and it is about saying we work

together…the patient by speaking to various people is going to get different responses back which can make it challenging for the patient and for us as a team, we've all got to be signing from the same hymn sheet… IV6

However even if the team are doing the latter,

…voices differ…one person can speak softly one can be assertive, the same phrase but the patient can take it a different way… IV6

4.4 Publicity

4.4.1 Media awareness

The impact of media awareness and the positive effect upon communications with people with cancer was commented on by three CNS's.

…I'd say everybody's ability to talk to patients about cancer has improved over the last 10-15 years so we're not having to correct misconceptions…people are talking about cancer far more… IV7

…[speciality] cancer has been in the news and the press…so you kind of use that for topical factors to aid your communication and get your point across… IV6

4.4.2. Internet

The internet was mentioned by two CNS's as having had an impact on the information levels of people with cancer and therefore the CNS's response.

…some people will already have looked things up on the internet we probably get into technical language quicker…I don't come across many patients that have been on the zany websites saying ridiculous things…if they have looked at anything it's pretty accurate… IV7

…they Google everything so they come with a load of rubbish…and you're constantly saying oh don't look at that and guide them to better sites… IV8

4.4.3. Literature

Literature was cited by two CNS's as an influence on their communication. The person can come to a consultation well informed,

…read up about x, y and z…" come to their appointment, *"…pre-educated…they are already a few steps ahead…* IV5

Continuity between written and spoken words is important to people with cancer,

…we give our patients cancer specific literature and information from charities and the hospital, so it's important to use the vocabulary used in these publications so they get some sort of continuity with what we're saying and what they're reading… IV6

CHAPTER 5

Discussion

5.1 Discussion

5.2 Limitations

5.1 Discussion

The findings answer the research question 'What factors influence the vocabulary CNS's in a DGH use when communicating with people with cancer?' The aims of the study have been addressed by revealing CNS's are aware not only of the vocabulary they use but that of the person with cancer and MDT members too. The CNS's reveal they regard the vocabulary of themselves, people with cancer and members of the MDT as important. The findings demonstrate how an array of factors have helped them to formulate and will continue to formulate their vocabulary. The findings show that CNS's do perceive their vocabulary has changed over time and identifies what factors have contributed to these changes.

This study demonstrates the importance of CNS's eliciting the vocabulary people with cancer use especially at pre-diagnosis and diagnosis. The study shows this serves three purposes for the CNS; it reveals the persons vocabulary, helps determine the 'entry level' of the vocabulary, reveals the person's thoughts on and understanding about what they understand. This in turn helps the CNS understand the person's level of health literacy, decide what vocabulary they use, which may include what the person with cancer has used and establish what if any misconceptions need to be clarified. Amalraj, Starkweather, Nguyen and Naeim (2009) highlight the importance of health literacy on patient-HP communications and the negative outcomes on people with cancer of inadequate health literacy including uninformed decision making.

Amalraj, Starkweather, Nguyen and Naeim (2009) describe how HP vocabulary can affect patient satisfaction and treatment concordance. High use of technical terms in HP focused complex 'dialogue dense' conversations do not meet

the health literacy level and needs of the majority of people with cancer and lead to poor satisfaction levels and poor outcomes (Amalraj, Starkweather, Nguyen and Naeim, 2009). Zeng and Tse (2006) describe the difference in laypersons and HP's terminology as the 'vocabulary gap'. For Zeng and Tse (2006) HP's create a barrier to health literacy through their use of technical terminology. This study provides new evidence that this is not true of the practice of the CNS's in the study.

The findings show that CNS's take steps to establish the health literacy of people with cancer. The steps include allowing the person with cancer to open up conversations, asking the person to clarify their understanding of words they use, avoiding terminology, using layman terms, providing literature using the same words they have spoken and using the word cancer at the earliest opportunity.

The study findings suggest that health literacy has improved. Three of the CNS's in the role for more than 10 years highlighted the internet and greater awareness of cancer as influences on the vocabulary they use. Sajid, Shakir and Baig, (2010) suggest 30-40% of cancer patients seek information on the internet. The three CNS's commented that the change is positive with people coming to consultations better informed and using more appropriate terms enabling them to pitch their communication and vocabulary at a higher 'entry level'. Whilst internet use has increased Sajid, Shakir and Baig, (2010) point out that the source of information most valued by people with cancer people with are HP's followed by printed materials, family and friends then the internet.

A key influence cited by all participants in the study is the vocabulary used by consultants/doctors. Data collected from the three CNS's in post for more than 10

years demonstrates that the vocabulary consultants/doctors use has become more honest and direct over the years but there remains a tendency for older consultants to continue to use metaphors or euphuisms instead of 'cancer'. The findings highlight the need for doctors to stop using euphuism and use the word 'cancer' and lay language throughout their communications, as indicated in the study by Rodriguez, Gambino, Butow, Hagerty and Arnold (2007). Dunn, Patterson, Butow, Smartt, McCarthy and Tattersall (1993) suggest the use of euphemism in an environment that indicates a suspicion of cancer e.g. cancer clinic, cancer diagnostic test can be harmful to the patient and prevent honest communication taking place between the person with cancer and the HP.

All CNS's in the study were clear they used the word cancer at the earliest opportunity. This resonates with the call of Susan Sontag (1991) to end the use of metaphor and speak plainly. A study by Dunn, Patterson, Butow, Smartt, McCarthy and Tattersall (1993) researched patient reaction to the word cancer as opposed to illness. The study found whilst use of 'cancer' increased patient anxiety levels, psychological adjustment was not affected and patients reported having a realistic view of their illness and were better able to consent to treatment.

When a cancer diagnosis is not confirmed but clinically there is a suspicion, the CNS's use what the study by Friedrichsen, Strang, and Carlsson (2002) describe as 'forewarning' words, words that forewarn of news to come. The CNS's do not use words such as polyp, lump or shadow they report using 'suspicious', 'abnormality', 'we are concerned about this'. In the study by Friedrichsen, Strang, and Carlsson (2002) participants felt the forewarning words used were 'fluff' words. It could be argued words such as polyp are fluff words as they are specific words

that have different meanings whereas 'suspicious' and 'abnormal' are descriptive non-specific words that in the cancer environment convey concern and alert the person to the need to be ready for possible bad news. If the patient suggested cancer as a possible diagnosis then the study shows the CNS's were open and honest in confirming cancer was suspected.

The study reveals the three CNS's with 10 years experience have noted a change in younger, newer doctors which they attribute to them benefiting from up-to-date communication training which should have included the ACST course. The study suggests CNS's perceive their vocabulary and communications to be more honest and direct than some of the doctors they work with. Kirklin (2007) suggests doctors who do not tell the truth deny the person their autonomy and right to be told the facts and make informed decisions based upon them. The findings corroborate those of Chapman, Abraham, Jenkins and Fallowfield (2003) who found people with cancer do not understand terminology used by doctors resulting in a lack of understanding and dissatisfaction with their care.

This study has provided new insight and knowledge into a previously undocumented role of the CNS, the detection, deciphering and decoding of what consultants and doctors have said to people. This study has also provided new insight and knowledge into the use of 'cancer' by CNS's and the way CNS's manage the vocabulary they use during communications with people being investigated for possible cancer.

A new finding is the triangulation of experience, knowledge and confidence and how pivotal and interconnected these three elements are in the personal and

professional development of the CNS. Various documents highlight the value of the CNS role; DH (2000b) (2010b), Leary and Oliver (2010), Macmillan Cancer Support (2010) and Royal College of Nursing (2010). These documents discuss the need for CNS's to have and develop experience and knowledge, however none of them discuss the confidence of CNS's and the impact of this on experience and knowledge. The only reference found to CNS confidence is in a study reviewing the effectiveness of the ACST course by Wilkinson, Blanchard and Linsell (2008). The study found nurses' confidence in communicating with people with cancer improved after attending the course. This study has revealed new data showing it takes up to two years for a CNS to feel confident in the role. No other data has been found to corroborate this finding. This study has discovered new knowledge regarding CNS confidence levels and the triangulation of experience, knowledge and confidence and the impact on communicating with people with cancer.

The findings of this study corroborate the finding by Wilkinson, Blanchard and Linsell (2008) that the ACST course is effective in improving the communication skills of nurses. Five CNS's voluntarily commented upon the importance of the ACST course in developing knowledge and skills. Three of the five were newer CNS's and they were especially vocal on the positive impact on their communication skills and confidence. Based on the evidence of this study it can be argued that the benefits of attending communication training courses are related to the length of time a CNS has been in post. For the five CNS's who had been in post for more than three years, training courses were best regarded as a reminder of what they should or should not be doing and were not seen as a major influence on their vocabulary. For the three newer CNS's the ACST course was cited as a significant influence on their vocabulary and communication skills. This finding shows the need

for course organisers and trainers to be mindful of the experience and skill mix of their audience.

The CNS's cite a number of personal and process factors as influences on the vocabulary they use. The CNS takes those positive and negative influences and adapts them to their own style, taste and characteristics to make their communications authentic, honest and natural. Of note is the CNS's decision not to include terminology found in cancer policy and strategy in their vocabulary as they find it unhelpful for people with cancer. Some CNS's were vociferous in their dislike of the terms 'survivor' and 'survivorship' with none of them referring to or viewing people with cancer in these terms.

Of interest is the view of CNS's in two specialities that the cancer the person has allows them to be more positive and hopeful in the vocabulary they use. Whilst the CNS's would not give false hope they do want to offer hope for the future where possible and feasible. It could be argued this approach is an example of the influence of positive communications on people with cancer outlined by Thorne, Hislop, Armstrong and Oglov (2007). Caution is required with this approach as many people will not see anything positive in being given a diagnosis of cancer even if the CNS does consider the type of cancer offers more favourable outcomes.

The study provides new insight concerning the challenge of CNS's working in teams as opposed to 'lone' CNS's. Three of the CNS's work in a team of CNS's with four consultants. Each person with cancer has a key worker however the CNS's deal with issues or queries from any person with cancer and work with all the consultants. With so many HP's involved the CNS's find a common shared

vocabulary provides some consistency of vocabulary and approach when speaking to people with cancer. The result is a 'we' approach to communication. None of these considerations were cited by lone working CNS's.

In a review of literature concerning cancer metaphors Harrington (2012) refers to multiple studies that demonstrate and advocate the widespread use of metaphors by cancer HP's. The findings of this study appear to contradict this. None of the CNS's mentioned using metaphors. One of the newer CNS's had used metaphors until they attended the ACST course which made them realise the metaphors they had used were not always appropriate. Harrington (2012) notes the value of HP's using metaphors used by people with cancer. All the CNS's said they try to elicit the language people with cancer use and use this back. It could be argued this should include metaphors that patients have used if appropriate. As all the CNS's said they would check any misunderstandings and dispel any misconceptions of language it can be assumed this would include any metaphors.

5.2 Limitations

The discovery of new insights into cancer communications which add to the existing body of knowledge demonstrates the study has strengths and benefits however, there are also a number of limitations. The study has been conducted with eight CNS's. Whilst this is an acceptable sample size for qualitative research the small number means the findings cannot be generalised to other CNS's. The study has been conducted in one DGH. The experiences of the CNS's are limited to this DGH and cannot be generalised to other DGH's or health care settings. The author of the study was known to the CNS's and part way through the study was appointed to a CNS role. It could be argued this may be a limitation to the study.

CHAPTER 6

Conclusion & recommendations

6.1 Conclusion

6.2 Recommendations

6.1 Conclusion

The study has answered the research question 'What factors influence the vocabulary CNS's in a DGH use when communicating with people with cancer?' The aims of the research study have been addressed as the findings demonstrate that CNS's are aware of the vocabulary they use, they do regard vocabulary as important, the study has identified how CNS's have and continue to formulate their vocabulary and has explored their perceptions of whether their vocabulary has changed over time.

The major influences on CNS's vocabulary are the people with cancer themselves, the personal experiences of the CNS, the process's the CNS operates within and the publicity that surrounds cancer. The study has shown how these influences have shaped the language and delivery of CNS cancer communications providing new insight to add to the existing body of knowledge. The findings have revealed new data on the interaction and interconnectedness of experience, knowledge and confidence and how these factors are core influences on the personal and professional development of the CNS and their vocabulary, communications and interaction with people with cancer and members of the MDT.

6.2 Recommendations

Recommendations are made based on the study findings. New CNS's should receive support during their first two years in the role to help build a triangulation of experience, knowledge and confidence. 'Lone' CNS's should have a 'buddy' CNS to discuss issues with and reflect on practice. The ACST course could be enhanced by prompting attendees to consider factors that influence their vocabulary. Further research is recommended to explore the impacts of team versus lone CNS working.

Research is recommended to examine the vocabulary people with differing levels of health literacy use and examine if the language and vocabulary CNS's are using match this. To strengthen the credibility, dependability, confirmability, transferability and authenticity of the findings consideration should be given to conducting the study in other DGH's within the UK.

Reference List

Amalraj, S., Starkweather, C., Nguyen, C., & Naeim, A. (2009). Health literacy, communication and treatment decision-making in older cancer patients [Electronic version]. *Oncology*, 23 (4), 369-375.

Appleton, L., & Flynn, M. (2012) *Report of a collaborative study exploring how the language and metaphor of cancer influences adjustment and well being following a course of cancer treatment* [Electronic version]. Unpublished qualitative research study, Clatterbridge Cancer Centre.

Cancer Research UK. (2013) *All cancer combined key facts.* Retrieved June 28, 2013, from: http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/uk-cancer-incidence-statistics

Chapman, K., Abraham, C., Jenkins., & Fallowfield, L. (2003). Lay understanding of terms used in cancer consultations [Electronic version]. *Psycho-oncology*, 12, 557-566.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: a practical guide for nurse researchers.* London, United Kingdom: SAGE Publications Ltd.

Denicolo, P., & Becker, L. (2012). *Developing research proposals.* London, United Kingdom: SAGE Publications Ltd.

Department of Health. (2000a). *The NHS cancer plan.* London, United Kingdom: The Stationary Office.

Department of Health. (2000b). *The nursing contribution to cancer care.* London, United Kingdom: The Stationary Office.

Department of Health. (2004). *Manual for cancer services.* London, United Kingdom: The Stationary Office.

Department of Health. (2005). *Research governance framework for health and social care.* (2nd ed.). Retrieved October 24, 2012, from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf

Department of Health. (2007a). *Getting it right for people with cancer*. London, United Kingdom: The Stationary Office.

Department of Health. (2007b). *Cancer reform strategy*. London, United Kingdom: The Stationary Office.

Department of Health. (2010a). *National cancer survivorship initiative*. Retrieved March 26, 2013, from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230

Department of Health. (2010b) *Excellence in cancer care: the contribution of the clinical nurse specialist.* London, United Kingdom: The Stationary Office.

Department of Health. (2011). *Improving Outcomes: a strategy for cancer*. London, United Kingdom: The Stationary Office.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview [Electronic version]. *Medical Education*, 40, 314-321.

Dunn, S. M., Patterson, P. U., Butow, P. N., Smartt, H. H., McCarthy, W. H., & Tattersall, M. H. N. (1993). Cancer by another name: a randomised trial of the effects of euphemism and uncertainty in communicating with cancer patients [Electronic version]. *Journal of Clinical Oncology*, 1 (5), 989-996.

Friedrichsen, M. J., Strang, P. M., & Carlsson, M. E. (2002). Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment. [Electronic version]. *Palliative Medicine*, 16, 323-330.

Grove, S. K., Burns, N., & Gray, J. R. (2013). *The practice of nursing research: appraisal, synthesis and generation of evidence.* (7th ed.). St. Louis, United States of America: Elsevier Saunders.

Hanne, M., & Hawken, S. J. (2007). Metaphors for illness in contemporary media [Electronic version]. *Medical Humanities*, 33, 93-99.

Harrington, K. J. (2012). The use of metaphor in discourse about cancer: a review of the literature [Electronic version]. *Clinical Journal of Oncology Nursing*, 16 (4), 408-412.

Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare.* Chichester, United Kingdom: Wiley-Blackwell.

Kirklin, D. (2007). Truth telling, autonomy and the role of metaphor [Electronic version]. *Journal of Medical Ethics*, 33, 11-14.

Krueger, R. A., & Casey, M. A. (2000). *Focus Groups: a practical guide for applied research.* (3rd ed.). Thousand Oaks, United States of America: SAGE Publications, Inc.

Kvale, S. (1996). *Interviews: an introduction to qualitative research interviewing.* London, United Kingdom: SAGE Publications Ltd.

Lanceley, A., & Macleod Clark, J. (2013). Cancer in other words? The role of metaphor in emotion disclosure in cancer patients. [Electronic version]. *British Journal of Psychotherapy*, 29 (2), 182-201.

Leadbeater, M., & Beaumont, T. (2010). Exploring terminology used in secondary breast cancer [Electronic version]. *Cancer Nursing Practice*, 9 (8), 21-24.

Leary, A., & Oliver, S. (2010). *Clinical nurse specialists: adding value to care: an executive summary.* London, United Kingdom: Royal College of Nursing.

Lewis, J., & Ritchie, J. (2003). Generalising from qualitative research. In J. Ritchie and J. Lewis (Ed.), *Qualitative research practice: a guide for social science students and researchers* (pp. 263-286). London, United Kingdom: SAGE Publications Ltd.

Macmillan Cancer Support. (2010). *Cancer clinical nurse specialists: an evidence review.* Retrieved November 8th, 2011, from: http://www.Macmillan.org.uk?servicesimpact

Mapp, T. (2008). Understanding phenomenology: the lived experience [Electronic version]. *British Journal of Midwifery*, 16 (5), 308-311.

Meadows, K. A. (2003a). So you want to do research? 2: developing the research question. *British Journal of Community Nursing*, 8 (9), 397-403.

Meadows, K. A. (2003b). So you want to do research? 3: an introduction to qualitative methods. *British Journal of Community Nursing*, 8 (10), 465-469.

NHS National Patient Safety Agency. (2012*). National research ethics service; information sheets and consent forms; guidance for researchers and reviewers.* Retrieved January 4, 2013 from: https://ganymede2.chester.ac.uk/view.php?title_id=618953

National Institute for Clinical Excellence. (2002). *Guidance on cancer services: improving outcomes in breast cancer: manual update.* London, United Kingdom: National Institute for Clinical Excellence.

Nursing and Midwifery Council. (2008). *The code: standards of conduct, performance and ethics for nurses and midwives.* London, United Kingdom: Nursing and Midwifery Council.

Parahoo, K. (2006). *Nursing research: principles, process and issues.* (2nd ed.). Basingstoke, United Kingdom: Palgrave Macmillan.

Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: methods, appraisal and utilisation.* (6th ed.). Philadelphia, United States of America: Lippincott Raven Publishers.

Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: methods, appraising evidence for nursing practice.* (7th ed.). Philadelphia, United States of America: Lippincott, Williams and Wilkins.

Razavi, D., Delvaux, N., Marchal, S., Durieux, J. F., Farvacques, C., Dubus, L., & Hogenraad, R. (2002). Does training increase the use of more emotionally laden words by nurses when talking with cancer patients ? A randomised trial [Electronic version]. *British Journal of Cancer*, 87 (1), 1-7.

Reisfield, G. M., & Wilson, G. R. (2004). Use of metaphor in the discourse on cancer. [Electronic version]. *Journal of Clinical Oncology*, 22 (19), 4024-4027.

Rodriguez, K. L., Gambino, F. J., Butow, P., Hagerty, R., & Arnold, R. M. (2007). Pushing up daisies: implicit and explicit language in oncologist-patient communication about death [Electronic version]. *Support Care Cancer*, 15, 153-161.

Royal College of Nursing. (2010). *Specialist nurses; changing lives, saving money.* London, United Kingdom: Royal College of Nursing.

Sajid, M. S., Shakir, A. J., & Baig, M. K. (2010). Information on the internet about colorectal cancer: patient attitude and potential toward web browsing. A prospective observational study [Electronic version]. *Canadian Journal of Surgery*, 54 (5), 339-343.

Silverman, D. (2010). *Doing qualitative research*. (3rd ed.). London, United Kingdom: SAGE Publications Ltd.

Siminoff, L. A., Graham, G. C., & Gordon, N. H. (2006). Cancer communication patterns and the influence of patient characteristics: disparities in information giving and affective behaviours. [Electronic version]. *Patient Education and Counselling*, 62, 355-360.

Sontag, S. (1991). *Illness as metaphor: aids and its metaphors.* London, United Kingdom: Penguin Books Ltd.

Spencer, L., Ritchie, J., & O'Connor, W. (2003). Carrying out qualitative analysis: generalising from qualitative research. In J. Ritchie and J. Lewis (Ed.), *Qualitative research practice: a guide for social science students and researchers* (pp. 219-262). London, United Kingdom: SAGE Publications Ltd.

Steen, M., & Roberts, T. (2011). *The handbook of midwifery research*. Chichester, United Kingdom: Wiley-Blackwell.

Streubert, H. J., and Carpenter, D. R. (2011). *Qualitative research in nursing: advancing the humanistic imperative*. (5th ed.). Philadelphia, United States of America: Lippincott, Williams & Wilkins.

Thorne, S. E., Hislop, T. G., Armstrong, E. A., & Oglov, V. (2008). Cancer care communication: The power to harm and the power to heal? [Electronic version]. *Patient Education and Counselling*, 71, 34-40.

Uitterhoeve, R., Bensing, J., Dilven, E., Donders, R., deMuider, P., & van Achterberg, T. (2009). Nurse-patient communication in cancer: does responding to patient's cues predict patient satisfaction with communication. [Electronic version]. *Psycho-Oncology,* 18, 1060-1068.

University of Chester. (2012). *Faculty of school of health and social care, research ethics sub committee: research project guidelines.* Retrieved November 24, 2012, from: https://ganymede.chester.ac.uk/index.php?page_id=1488138&group=14

Whitting, L. S. (2007). Semi-structured interviews: guidance for novice researchers [Electronic version]. *Nursing Standard*, 22 (23), 35-40.

Wilkinson, S., Blanchard, K., & Linsell, L. (2008). Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial [Electronic version]. *Palliative Medicine*, 22, 365-375.

Zeng, Q. T., Tse, T. (2006). Exploring and developing consumer health vocabularies [Electronic version]. *Journal of the American Medical Informatics Association*, 13 (1), 24-29.

Bibliography

Amalraj, S., Starkweather, C., Nguyen, C., & Naeim, A. (2009). Health literacy, communication and treatment decision-making in older cancer patients [Electronic version]. *Oncology*, 23 (4), 369-375.

Appleton, L., & Flynn, M. (2012) *Report of a collaborative study exploring how the language and metaphor of cancer influences adjustment and well being following a course of cancer treatment* [Electronic version]. Unpublished qualitative research study, Clatterbridge Cancer Centre.

Burns, N., & Grove, S. K. (2003). *Understanding nursing research*. (3rd ed.). Philadelphia, United States of America: Saunders.

Brown, P. R., Alaszewski, A., Swift, T., & Nordin, A. Actions speak louder than words: the embodiment of trust by healthcare professionals in gynae-oncology. [Electronic version]. *Sociology of Health and Illness*, 33 (2), 280-295.

Cancer Research UK. (2013) All cancer combined key facts. Retrieved June 28, 2013, from: http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/uk-cancer-incidence-statistics

Chapman, K., Abraham, C., Jenkins., & Fallowfield, L. (2003). Lay understanding of terms used in cancer consultations [Electronic version]. *Psycho-oncology*, 12, 557-566.

Charlton, C. R., Dearing, K. S., Berry, J. A., & Johnson, M. J. (2008). Nurse practitioners' communication styles and their impact on patient outcomes: an integrated literature review [Electronic version]. *Journal of American academy of nurse practitioner*s, 20 (7), 382-387.

Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: a practical guide for nurse researchers*. London, United Kingdom: SAGE Publications Ltd.

Dempsey, P. A., & Dempsey, A. D. (2000). *Using nursing research: process, critical evaluation and utilisation*. (5th ed.). Philadelphia, United States of America: Lippincott, Williams & Wilkins.

Denicolo, P., & Becker, L. (2012). *Developing research proposals*. London, United Kingdom: SAGE Publications Ltd.

Department of Health. (2000a). *The NHS cancer plan*. London, United Kingdom: The Stationary Office.

Department of Health. (2000b). *The nursing contribution to cancer care*. London, United Kingdom: The Stationary Office.

Department of Health. (2004). *Manual for cancer services*. London, United Kingdom: The Stationary Office.

Department of Health. (2005). *Research governance framework for health and social care.* (2nd ed.). Retrieved October 24, 2012, from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf

Department of Health. (2007a). *Getting it right for people with cancer*. London, United Kingdom: The Stationary Office.

Department of Health. (2007b).*Cancer reform strategy*. London, United Kingdom: The Stationary Office.

Department of Health. (2010a). *National cancer survivorship initiative*. Retrieved March 26, 2013, from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111230

Department of Health. (2010b). *Excellence in cancer care: the contribution of the clinical nurse specialist*. London, United Kingdom: The Stationary Office.

Department of Health. (2010b) *Excellence in cancer care: the contribution of the clinical nurse specialist.* London, United Kingdom: The Stationary Office.

Department of Health. (2011). *Improving Outcomes: a strategy for cancer*. London, United Kingdom: The Stationary Office.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview [Electronic version]. *Medical Education*, 40, 314-321.

Dunn, S. M., Patterson, P. U., Butow, P. N., Smartt, H. H., McCarthy, W. H., & Tattersall, M. H. N. (1993). Cancer by another name: a randomised trial of the effects of euphemism and uncertainty in communicating with cancer patients [Electronic version]. *Journal of Clinical Oncology*, 1 (5), 989-996.

Flick, E. (2009). *An introduction to qualitative research*. (4th ed.). London, United Kingdom: SAGE Publications Ltd.

Friedrichsen, M. J., Strang, P. M., & Carlsson, M. E. (2002). Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment. [Electronic version]. *Palliative Medicine*, 16, 323-330.

Grove, S. K., Burns, N., & Gray, J. R. (2013). The practice of nursing research: appraisal, synthesis and generation of evidence. (7th ed.). St. Louis: United States of America: Elsevier Saunders.

Hanne, M., & Hawken, S. J. (2007). Metaphors for illness in contemporary media [Electronic version]. *Medical Humanities*, 33, 93-99.

Harrington, K. J. (2012). The use of metaphor in discourse about cancer: a review of the literature [Electronic version]. *Clinical Journal of Oncology Nursing*, 16 (4), 408-412.

Hart, C. (2001). *Doing a literature search: a comprehensive guide for the social sciences*. London, United Kingdom: SAGE Publications Ltd.

Holloway, I., & Wheeler, S. (2010). *Qualitative research in nursing and healthcare*. Chichester, United Kingdom: Wiley-Blackwell.

Kirklin, D. (2007). Truth telling, autonomy and the role of metaphor [Electronic version]. *Journal of Medical Ethics*, 33, 11-14.

Krueger, R. A., & Casey, M. A. (2000). *Focus Groups: a practical guide for applied research*. (3rd ed.). Thousand Oaks, United States of America: SAGE Publications, Inc.

Kvale, S. (1996). *Interviews: an introduction to qualitative research interviewing*. London, United Kingdom: SAGE Publications Ltd.

Lanceley, A., & Macleod Clark, J. (2013). Cancer in other words? The role of metaphor in emotion disclosure in cancer patients. [Electronic version]. *British Journal of Psychotherapy*, 29 (2), 182-201.

Leadbeater, M., & Beaumont, T. (2010). Exploring terminology used in secondary breast cancer [Electronic version]. *Cancer Nursing Practice*, 9 (8) 21-24.

Leary, A., & Oliver, S. (2010). *Clinical nurse specialists: adding value to care: an executive summary.* London, United Kingdom: Royal College of Nursing.

Lewis, J., & Ritchie, J. (2003). Generalising from qualitative research. In J. Ritchie and J. Lewis (Ed.), *Qualitative research practice: a guide for social science students and researchers* (pp. 263-286). London, United Kingdom: SAGE Publications Ltd.

Lobb, E. A., Butow, P. N., Kenny, D. T., & Tattersall, M. H. N. (1999). Communicating prognosis in early breast cancer: do women understand the language used? [Electronic version}. *Medical Journal of Australia*, 171, 290-294.

Macmillan Cancer Support. (2010). *Cancer clinical nurse specialists: an evidence review.* Retrieved November 8th, 2011, from: http://www.Macmillan.org.uk?servicesimpact

Mapp, T. (2008). Understanding phenomenology: the lived experience [Electronic version]. *British Journal of Midwifery*, 16 (5), 308-311.

Meadows, K. A. (2003a). So you want to do research? 2: developing the research question. *British Journal of Community Nursing*, 8 (9), 397-403.

Meadows, K. A. (2003b). So you want to do research? 3: an introduction to qualitative methods. *British Journal of Community Nursing*, 8 (10), 465-469.

Merckaert, I., Libert, Y., Delvaux, N., Marchal, S., Boniver, J., Etienne, A. M., Kiastersky, J., Reynaert, C., Scalliet, P., Slachmuylder, J. l., & Razavi, D. (2005). Factors that influence physicians' detection of distress in patients with cancer. *Cancer*, 104 (2), 411-421.

NHS National Patient Safety Agency. (2012*). National research ethics service; information sheets and consent forms; guidance for researchers and reviewers.* Retrieved January 4, 2013 from: https://ganymede2.chester.ac.uk/view.php?title_id=618953

National Institute for Clinical Excellence. (2002). *Guidance on cancer services: improving outcomes in breast cancer: manual update.* London, United Kingdom: National Institute for Clinical Excellence.

National Institute for Clinical Excellence. (2004). *Guidance on cancer services: improving supportive and palliative care for adults with cancer; the manual.* London, United Kingdom: National Institute for Clinical Excellence.

Nursing and Midwifery Council. (2008). *The code: standards of conduct, performance and ethics for nurses and midwives.* London, United Kingdom: Nursing and Midwifery Council.

Parahoo, K. (2006). *Nursing research: principles, process and issues.* (2nd ed.). Basingstoke, United Kingdom: Palgrave Macmillan.

Peterson, M., & Fretz, C. Patient use of the internet for information in a lung cancer clinic [Electronic version]. *Chest*, 123 (2), 452-457.

Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: methods, appraisal and utilisation.* (6th ed.). Philadelphia, United States of America: Lippincott Raven Publishers.

Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: methods, appraising evidence for nursing practice.* (7th ed.). Philadelphia, United States of America: Lippincott, Williams and Wilkins.

Razavi, D., Delvaux, N., Marchal, S., Durieux, J. F., Farvacques, C., Dubus, L., & Hogenraad, R. (2002). Does training increase the use of more emotionally laden words by nurses when talking with cancer patients? A randomised trial [Electronic version]. *British Journal of Cancer*, 87 (1), 1-7.

Reisfield, G. M., & Wilson, G. R. (2004). Use of metaphor in the discourse on cancer. [Electronic version]. *Journal of Clinical Oncology*, 22 (19), 4024-4027.

Rodriguez, K. L., Gambino, F. J., Butow, P., Hagerty, R., & Arnold, R. M. (2007). Pushing up daisies: implicit and explicit language in oncologist-patient communication about death [Electronic version]. *Support Care Cancer*, 15, 153-161.

Royal College of Nursing. (2010). *Specialist nurses; changing lives, saving money.* London, United Kingdom: Royal College of Nursing.

Sajid, M. S., Shakir, A. J., & Baig, M. K. (2010). Information on the internet about colorectal cancer: patient attitude and potential toward web browsing. A prospective observational study [Electronic version]. *Canadian Journal of Surgery*, 54 (5), 339-343.

Seidman, I. (2006). *Interviewing as qualitative research: a guide for researchers in education and the social sciences.* (3rd ed.). New York, United States of America: Teachers College Press.

Shala, M., Wenzel, J., & Hill, E. (2011). Planning and conducting focus group research with nurses [Electronic version*]. Nurse Researcher*, 18 (2), 77-87.

Silverman, D. (2010). *Doing qualitative research.* (3rd ed.). London, United Kingdom: SAGE Publications Ltd.

Siminoff, L. A., Graham, G. C., & Gordon, N. H. (2006). Cancer communication patterns and the influence of patient characteristics: disparities in information giving and affective behaviours. [Electronic version]. *Patient Education and Counselling*, 62, 355-360.

Smith, C. A. (2011). Consumer language, patient language and thesauri: a review of the literature [Electronic version]. *Journal of the Medical Library Association*, 99 (2), 135-142.

Singh, K., & Hodgson, D. (2011). How can the multi-disciplinary team meet the psychological needs of adolescents with cancer [Electronic version]. *Journal of Radiotherapy in Practice*, 10, 55-64.

Sontag, S. (1991). *Illness as metaphor: aids and its metaphors.* London, United Kingdom: Penguin Books Ltd.

Spencer, L., Ritchie, J., & O'Connor, W. (2003). Carrying out qualitative analysis: generalising from qualitative research. In J. Ritchie and J. Lewis (Ed.), *Qualitative research practice: a guide for social science students and researchers* (pp. 219-262). London, United Kingdom: SAGE Publications Ltd.

Steen, M., & Roberts, T. (2011). *The handbook of midwifery research.* Chichester, United Kingdom: Wiley-Blackwell.

Streubert, H. J., and Carpenter, D. R. (2011). *Qualitative research in nursing: advancing the humanistic imperative.* (5th ed.). Philadelphia, United States of America: Lippincott, Williams & Wilkins.

Thorne, S. E., Hislop, T. G., Armstrong, E. A., & Oglov, V. (2008). Cancer care communication: the power to harm and the power to heal? [Electronic version]. *Patient Education and Counselling*, 71, 34-40.

Uitterhoeve, R., Bensing, J., Dilven, E., Donders, R., deMuider, P., & van Achterberg, T. (2009). Nurse-patient communication in cancer: does responding to patient's cues predict patient satisfaction with communication. [Electronic version]. *Psycho-Oncology,* 18, 1060-1068.

University of Chester. (2012). *Faculty of school of health and social care, research ethics sub committee: research project guidelines.* Retrieved November 24, 2012, from: https://ganymede.chester.ac.uk/index.php?page_id=1488138&group=14

Whitting, L. S. (2007). Semi-structured interviews: guidance for novice researchers [Electronic version]. *Nursing Standard*, 22 (23), 35-40.

Wilkinson, S. (1991). Factors which influence how nurses communicate with cancer patients. [Electronic version]. *Journal of Advanced Nursing*, 16, 677-688.

Wilkinson, S., Blanchard, K., & Linsell, L. (2008). Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial [Electronic version]. *Palliative Medicine*, 22, 365-375.

Willard, C., & Luker, K. (2007). Working with the team: strategies employed by hospital cancer nurse specialists to implement their role [Electronic version]. *Journal of Clinical Nursing*, 16, 716-724.

Zeng, Q. T., Tse, T. (2006). Exploring and developing consumer health vocabularies [Electronic version]. *Journal of the American Medical Informatics Association*, 13 (1), 24-29.

Key words and concepts for literature search

Initial search

Cancer AND

specialist nurs*	communicat*	language	style
patient	vocabulary	metaphor*	word*
influenc*	perception	terminology	

Narrowing techniques:

Refine your search	limit to articles from scholarly publications including peer reviewed
Content type	Journal article
Publication date	1/1/2000 – 30/6/2013

Using 'Library Search' facility

Appendix 2

Interview Guide

2 mins	General conversation to build rapport e.g. what sort of day the CNS has had
3 mins	Confirm still happy to participate Sign consent form Reminder that interview will be audio recorded Advise the researcher will make notes throughout the interview Encourage the CNS to ask for clarification if any questions are unclear Confirm pseudonym has been allocated to the CNS and name will not appear on recording Reiterate can stop interview at any point if not happy Reiterate interview will last no longer than 60 minutes Confirm can withdraw from study at any point in the future Reiterate than lead CNS available for CNS to talk to regarding any issues the interview has raised Reiterate that lead CNS and Research Manager at DGH and Dean of Faculty of Health and Social Care at University of Chester available if they have any issues or concerns with the study, the process or the researcher Confirm information shared is private and confidential
5 mins	The aim of the study is to understand what factors influence the vocabulary used by CNS's. I'd like to begin by your thinking for a moment about the vocabulary (words) you use in your communications with people with cancer: - What particular words or phrases do you use? - How aware would you say you are of using these words?
10 mins	Having thought about and discussed the vocabulary you use, I'd like to explore whether you feel vocabulary is an important aspect of cancer communication - How important would you say vocabulary is? - Thinking about the words you have identified, how do you think people with cancer may perceive or interpret these words?
20 mins	I'd like to explore with you the factors that have influenced your adopting these words into your vocabulary;

	- What factors do you feel have influenced your use of these words? - If you were to rank the factors with the first being the most influential and the last being the least influential, what order would you place them in?
15 mins	Having identified the factors that have influenced your vocabulary, I'd like to explore with you; - your perceptions of whether your vocabulary has changed over time - what factors, if any, may have influenced this change.
5 mins	Bring interview to close Ask CNS if anything further especially want to mention Thank CNS for their time and contribution

Appendix 3

Invitation to participate letter

Researchers address
Date

Dear <INSERT NAME> - Cancer Nurse Specialist for <INSERT SPECIALITY>

You are being invited to take part in a research study that has received ethical approval from the University of Chester Research Ethics Committee and agreement from <INSERT NAME OF DGH RESEARCH MANAGER AND LEAD CNS>. The study is entitled;

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).

The main aim of the study is to explore factors that influence the vocabulary CNS's use when communicating with people with cancer.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the enclosed participant information sheet carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Your participation is entirely voluntary and can only be conducted with your informed written consent. You are free to withdraw from the study at any time. The information you provide will be anonymous and confidential and cannot be linked back to you as an individual.

If, having read the participant information sheet and consent form, you would like to take part please complete the enclosed reply slip and post it using the stamped-addressed envelope by <INSERT DATE>. Participants will be contacted by letter by <INSERT DATE> to arrange a mutually convenient date and time to conduct the research

If you have any questions concerning this study or require clarification of any points in the information sheet please contact me on <INSERT CONTACT DETAIKS OF RESEARCHER>. If you have any concerns of issues regarding the study please contact <INSERT NAME OF LEAD CNS>.

Thank you for considering this request.

Yours sincerely

<INSERT RESEARCHERS NAME>

RESPONSE SLIP

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).

Having read the participant information sheet and consent form, I am interested in taking part in the above study.

NAME: …………………………………………………….

SPECIALITY: ……………………………………………..

WORK CONTACT NUMBER: …………………………………… BLEEP: ………….

SIGNATURE: ……………………………………………

DATE: …………………………………

Appendix 4

Participant information sheet   <INSERT DATE>

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).

What is the purpose of the study?
In a simulated interview counselling a woman given a diagnosis of breast cancer I was challenged by her negative reaction to my use of the word 'journey'. This led me to reflect on the vocabulary I use and consider the potential harm this could cause. The significance attached to words used by health professionals (HP's) is demonstrated in a 2012 study by L. Appleton and M. Flynn, research nurses at Clatterbridge Cancer Centre. The study found language had positive and negative impacts on the experiences of people touched by cancer.

Following my experience and Appleton & Flynn's call for more research into the specifics of language used by HP's, the main aim of the study is to explore factors that influence the vocabulary CNS's use when communicating with people with cancer.

Why have I been chosen?
The research concerns the vocabulary used by CNS's, as such all CNS's at the <INSERT NAME OF DGH> have been invited to take part.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?
The study can accommodate up to eight participants. Should more that eight CNS's agree to take part, the names will be written on identical slips of white paper and placed in a Scrabble tile bag with <INSERT NAME OF LEAD CNS> randomly selecting eight slips.

Should you be selected, you will receive a letter offering a choice of dates to take part in a one-to-one interview with myself as the researcher. The interview is expected to last between 45 – 60 minutes and will take place in an interview room in the executive suite. The interview will be audio recorded. The date and time of the interview will be agreed with each CNS individually to suit work and home commitments. Light refreshments will be provided. CNS's not selected will be notified in writing.

If you decide to take part, you will be given this information sheet to keep and asked to sign the consent form. This will give your consent for the researcher to invite you to attend a one-to-one interview.

What are the possible disadvantages and risks of taking part?
There are no disadvantages or risks foreseen in taking part in the study. <INSERT NAME OF LEAD CNS> will be available to discuss any issues or concerns raised by the interview process and/or discussion.

What are the possible benefits of taking part?
As a CNS it is possible that you may welcome the opportunity to share and discuss your views and experiences with the researcher. By taking part, you will be contributing to the

body of knowledge concerning communications with people with cancer. The experience may cause you to reflect upon and possibly adapt the vocabulary you use. Publication of the research findings may help inform other CNS's and health professionals. The ultimate benefit is to see if the quality of the communications and interactions CNS's have with people with cancer can be improved upon.

What if something goes wrong?
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact one or all of the following people < INSERT NAMES OF LEAD CNS , DGH RESEARCH MANAGER, DEAN OF THE FACULTY OF HEALTH AND SOCIAL CARE, UNIVERSITY OF CHESTER>

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence (but not otherwise), then you may have grounds for legal action, but you may have to pay for this.

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept anonymous and strictly confidential. The researcher will allocate you a pseudonym which will be used throughout the research process. The audio recoding will not contain your name. Participant details and pseudonyms will be kept in double locked facilities.. The recording and all data will be kept in separate double locked facilities. These facilities will only be accessible to the researcher. The recoding and data will be kept for two years after the research has been conducted after which it will be destroyed using confidential waste systems.

What will happen to the results of the research study?
The results will be written up into a report, a copy of which will be sent to you for your validation prior to any public dissemination or publication. The report will be sent to <INSERT NAME OF:
-   LEAD CNS AND RESEARCH MANAGER AT DGH
-   CONTACT NAME AT LOCAL CANCER NETWORK
-   NAMES OF LEAD CNS's AT LOCAL CANCER CENTRE
-   NAME OF MACMILLAN NURSE AT DGH
-   NAME OF LEAD LECTURER AT CANCER CENTRE EDUCATION CENTRE >

It is hoped that the findings will be published in relevant academic journals. The aim of all dissemination and publication will be to add to the body of knowledge and improve the care of people with cancer.

Who is organising and funding the research?
The research is organised and funded by the researcher. The researcher is a Registered General Nurse working on <INSERT NAME OF WARD>. The study is being conducted as part of a Masters programme.

Who may I contact for further information?
If you would like more information about the research before you decide whether or not you would be willing to take part, please contact, <INSERT NAME AND CONTACT DETAILS OF RESEARCHER>*.*

Thank you for your interest in this research.

Appendix 5

Consent Form

Title of Project:

<u>A qualitative study to explore factors that influence the vocabulary used by</u>
<u>Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).</u>

Name of Researcher: <INSERT NAME>

Please initial box

1.   I confirm that I have read and understood the
      participant information sheet, dated <INSERT DATE>,
      for the above study and have had the opportunity
      to ask questions.

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

3.   I agree to take part in a one-to-one interview with the
      researcher, to the interview being audio recorded and the
      transcript being used for analysis.

4.   I agree to the use of anonymised, direct quotes being used
      in the report and any publication of the research findings

5.   I agree to take part in the above study.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person taking consent   Date   Signature
(if different from researcher)

_____   _____   _____
Researcher   Date   Signature

Appendix 6

Confirmation letter of unsuccessful selection to participate

<div align="right">Researchers address
Date</div>

Dear <INSERT NAME> - Cancer Nurse Specialist for <INSERT SPECIALITY>

<div align="center">

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).

</div>

Thank you for your interest in the above research study and interest in taking part.

There has been a fantastic response with more than eight CNS's responding to the invitation letter. In accordance with the process outlined in the participant information sheet, the names were written on identical slips of white paper and placed in a Scrabble tile bag from which <INSERT NAME OF LEAD CNS> randomly selected eight slips.

I am sorry to say your name was not selected.

Your interest is appreciated and I thank you once again for taking the time to read the information and respond.

Yours sincerely

<INSERT   RESEARCHERS   NAME>

Appendix 7

Confirmation letter of participation

<div align="right">
Researchers address
Date
</div>

Dear <INSERT NAME> - Cancer Nurse Specialist for <INSERT SPECIALITY>

A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH).

Thank you for your interest in the above research study and interest in taking part.
<<
<INSERT IF MORE THAN EIGHT CNS's RESPOND>
There has been a fantastic response with more than eight CNS's responding to the invitation letter. In accordance with the process outlined in the participant information sheet, the names were written on identical slips of white paper and placed in a Scrabble tile bag from which <INSERT NAME OF LEAD CNS> randomly selected eight slips. I am pleased to advise your name was selected.

<INSERT IF LESS THAN EIGHT CNS's RESPOND>
As less than eight CNS's responded there is no need adopt the process outlined in the participant information sheet. I am please to advise you will be a participant in this study
>>

The following dates are available to conduct the interview which will last between 45-60 minutes.
<INSERT DATES>
I am available all day on these dates and am happy to agree a time convenient for you. Please contact me by <INSERT DATE> on <INSERT CONTACT NUMBERS> to agree a time. If I am unable to take your call, please leave a message and a contact telephone number and I will return your call.

Once again, thank you for agreeing to take part and I look forward to hearing from you.

Yours sincerely

<INSERT RESEARCHERS NAME>

Appendix 8

University of Chester ethical approval letter

EMW/bh

15th March 2013

University of
Chester

Faculty of Health and Social Care

Tel 01244 511000
Fax 01244 511270

Ethical Approval Granted

FH&SC Ethics Number: RESC0213-396
Course of Study: MSc Professional Practice
Supervisor:
Student Number:

I am pleased to inform you that the Research Ethics Sub Committee of the Faculty of Health and Social Care have approved your project **"A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH)."**

Approval is subject to the above and following conditions:

1.   That you provide a brief report for the sub-committee on the completion of your project.
2.   That you inform the sub-committee of any substantive changes to the project.

We approve your application to go forward to the next stage of the approval process. If you are applying to IRAS and require a sponsorship letter and insurance documentation please contact

Yours sincerely

Chair, Faculty Research Ethics Sub-Committee

cc   Research Knowledge Transfer Office
cc   Academic Supervisor

University of Chester, Riverside, Castle Drive, Chester, CH1 1SL
Founded in 1839 by the Church of England • Registered Charity № 525938 • "Working towards Equality of Opportunity • Extending Opportunities through Education

94

Appendix 9

DGH research project approval letter

Research & Innovation Department

20th March 2013

CONFIDENTIAL

Study Title: **A qualitative study to explore factors that influence the vocabulary used by Cancer Nurse Specialists (CNS) in a District General Hospital (DGH)**
REC Ref: **RESC0213-396**
R&D Ref: **Stud070/13**

The Research & Innovation Department is pleased to approve this project, together with the indemnity and financial assessments and hopes that it proves to be interesting and rewarding.

You are reminded that although this project has been approved by the Trust, all research must also have appropriate ethical committee approval **before** it is undertaken.

As part of research governance, the Research & Innovation Department is required to monitor the progress and outcome of research within the Trust. Therefore, whilst this project continues Mrs Sheila Williams, Research Manager will be in contact annually to request a brief update and the Research & Innovation Department would be grateful for a summary on completion of the project, (if available, a copy of any publication or an abstract of a presentation relating to this study would suffice).

Conditions of approval

In addition, please note you must inform us if your project deviates in any way from the original proposal/documentation you have submitted. Your approval is limited to the dates stated on the research application form and that you are obliged to notify the Research & Innovation Department of any adverse events that arise during the course of the project. May I remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care (2005). If it is found that this is not the case, this may result in the suspension of your project until changes have been agreed with the Trust, or your research may be terminated pending an enquiry.

Permissions

95

This letter authorises you in principle to undertake research within the Trust. However, it is your responsibility to ensure that individuals appropriate to your work have no objections to your studies. This department accepts no liability for non co-operation of staffs or patients.

Auditing

I would strongly urge you to maintain an accurate and up to date site file for your documentation, as the Trust randomly audits projects to assess compliance with the relevant frameworks and legislation. If your study is chosen, you will be notified in writing not less than two weeks prior to the required submission date of documentation.

Reporting

In the interest of ensuring the Trust receives maximum benefit from co-operating with research projects such as your own, the Trust places great importance on disseminating findings and conclusions. Therefore we would welcome a short summary of the findings of this project, once completed, along with any formal publications resulting from this work.

I would like to take this opportunity to wish you well with your project. If you have any questions or I can be of any further assistance to you, please do not hesitate to contact me.

Yours sincerely