Adams, Katherine (2010) How confident are community nurses in caring for patients who are dying? A qualitative study of community nurses' experience's of providing end of life care in the community. [Dissertation (University of Nottingham only)] (Unpublished)

How confident are community nurses in caring for patients who are dying?

A qualitative study of community nurses' experience's of providing end of life care in the community

Katherine Adams

Dissertation submitted for Master of Nursing Science, School of Nursing, Midwifery and Physiotherapy, Faculty of Medicine, University of Nottingham

"I declare that this dissertation is my own work"

Signed …………………………………………………………………..

Date …………………………….

Acknowledgements

I would firstly like to thank my supervisor, Kristian Pollock, for all the time she gave as I undertook this work, as well as for answering my many questions, encouraging me to think more widely about the issues involved and for holding supervisory sessions that always left me feeling like I was able to complete this study.

Alongside this, I would like to acknowledge and thank all the community nurses who agreed to take part in this study, for the time they put aside to talk to me.

Thanks must go to my student nurse friends, particularly my house mates and others who joined in with the comfort cooking!

Thank you to my parents for all of your support throughout the whole course.

Lastly, thank you Graham, for gently encouraging me from the other side of the world.

Contents

Chapter Five: Discussion _____**46**

Chapter Six: Conclusion _____**57**

References _____**vi**

Appendices_____**xv**

List of Tables

Word Count: 15, 956

Abstract

Aim

The purpose of this study was to explore how confident community nurses are in providing end of life care in the community.

Background

The amount of palliative care being provided in the community is growing as more patients are deciding to die at home. Community nurses are the community professionals who are taking on the primary role of caring for these patients. Literature has considered the experiences of this population (Wilkes and Beale, 2001; Rose and Glass, 2006; Seale, 1992); however, there is little that addresses how confident community nurses are in providing this care.

Method

Ten semi-structured interviews were completed with community nurses involved in palliative care, utilising an interpretive phenomenological approach. The interviews were recorded and subsequently analysed using Giorgi's framework of analysis (1985).

Findings

The five main theme categories that were identified were confidence, providing palliative care, experience, training and support. Although forming separate categories, the themes were also interwoven, forming a complex picture of the confidence of community nurses.

Conclusions

The picture that the community nurses presented was of confidence being a complex layered phenomenon. Professionally, they appeared confident in their role. Behind this, however, they were less confident in certain aspects of the work

and their ability to provide the care. It was seen as possible to increase confidence, largely through experience of the role and mentoring through practice. Training was also seen to be important, but not as significant as is presented in recent policies and strategies. Central to growing in confidence and maintaining confidence was a support network, comprising of organisational structures as well as interpersonal relationships with colleagues and the wider community team.

Chapter One

Introduction

1.1   <u>**Background and Rationale for the Study**</u>

Caring for a patient who is dying is not a role simply for those who chose to specialise in the area, but is something that will be encountered in many areas of nursing. The World Health Organisation defines palliative care as the "approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness" (WHO, 2010). Whether working on an acute medical ward, an oncology ward or in the community, there will be patients who are reaching the end stages of life and therefore require care appropriate to this. For nurses who are not given suitable training for this role, there can be many difficulties and stressful situations that arise. In addition to this, significant pressure is added simply because it is the last days of a patient's life – there is only one chance to get it right. These stressors are magnified in the community when a patient is in their own home and environment with their family around.

Since William Rathbone employed a nurse to care for his dying wife at home in 1859 (QNI, 2008), palliative care has been carried out by community nurses within a patient's own home, enabling them to live the remainder of their life within their own environment. From my experience working alongside community nurses on a community placement, excellent care was provided for the palliative patients despite the nurses having little preparation specifically for that role. However, on discussion with a number of the nurses, there was clearly a difference in how they viewed their work. One felt that she had provided quality care and done her best. Another however stated that she often questioned whether enough had been done and doubted that the care she provided was satisfactory. As an observer, there was no obvious difference in the provision of care. Instead it appeared to be an issue of confidence and self awareness.

A review of the literature showed that the research into palliative care in general is growing, as is the literature looking at those carrying out this care. Current studies have considered the experiences of community nurses and some of the areas that cause stress, as well as how community nurses cope with that stress (Wilkes and Beale, 2001; Rose and Glass, 2006; Seale, 1992). However it appears that the confidence of community nurses in providing care for the dying has not been studied in depth. At present, approximately 18% of people chose to die in their own homes, and it is hoped that this will increase to 25% (DoH, 2008). Community nurses will be the work force to take on this increased work load and it is uncertain whether they are adequately prepared to do so. With this in mind, it appears crucial that more research is carried out looking at this population and how confident they feel in providing palliative care. Thus, the following aims and objectives have been identified for this research study.

1.2   **Aims and Objectives**

Aims:

This study aims to investigate how confident community nurses are in providing end of life care in the community.

Objectives:

- To establish how confident community nurses feel in providing end of life care.
- To identify the perceptions of community nurses on the preparation and training they receive to take on this role and whether they feel this is adequate.
- To determine the perceptions of community nurses on the support available to them and whether this enables them to provide end of life care.

Chapter Two

Literature Review

2.1   Chapter Introduction

A brief literature review was initially carried out to formulate a research question and provide the basis for a research proposal for this study, with a more extensive review following to provide a foundation for the findings and place the study in context.   Literature was identified in online and printed journals, the university library and several government documents.   A search of Cinahl and the British Nursing Index used the keywords in various combinations: community nurse; district nurse; palliative care; end of life care; confidence; experience; support and training.   Articles identified were used within this literature review if they considered the experiences or confidence of community nurses, and were accessible.

The literature identified appeared to veer either towards investigating the patient's or carer's experiences of palliative care at home or towards issues involving the nurse providing the care.   The literature available on the subject of the nurse providing palliative care in the community was not vast (Austin et al, 2000), however what was available covered a significant cross section of the issues encountered by community nurses (Rose and Glass, 2000).   This chapter will therefore be split into three sections considering the literature in these areas: the community nurse providing palliative care, the training available and the support available.

2.2   The Community Nurse Providing Palliative Care

The community nurse has been identified as the health professional who commonly has the most contact with palliative patients in the community (Grande et al, 1996). This places them in an ideal position to take on the role of key worker, co-ordinating the efforts of all those working with palliative patients (Dunne et al,

3

2005). Despite this, it is often the General Practitioner (GP) who is seen to co-ordinate a patient's care (Field, 1998). Frequently mentioned within the literature is a suggestion that the role of the community nurse in palliative care is ill defined (Goodman et al, 1998; Griffiths et al, 2007; Wright, 2002). Palliative patients in one study stated that they believed that the community nurses involved in their care would provide the physical care, whilst the MacMillan nurses would provide the emotional support (Grande et al, 1996). In reality, both of these elements form part of the community nurses role, but this was not made clear to the patients. It could be argued that this indicates that patients are confused by the large number of health professionals involved in their care, rather than role ambiguity of the community nurses. However the lack of effective communication about their role to patients does imply that the community nurses are not clear on this themselves. This role ambiguity can be seen as the cause of dilemmas for the nurses carrying out the care, inducing significant stress (Griffiths et al, 2007).

It has been argued that the literature considering this role ambiguity should perhaps be viewed in light of significant changes in the nature of community nursing work (Austin et al, 2000). To name a few, changes in government policy transferred some of the work traditionally carried out by the community nurse to the social sector. This predominately meant that the community nurse was no longer involved in the personal care of patients. However, this shift in work load was met with an increasing emphasis on patients having more choice about where they want to die (DoH, 2008). Alongside this, the NHS turned towards a market economy; ensuring that services provide best value for money, but budget and staffing cuts were made (Austin et al, 2000). Throughout the time that these changes occurred, the impact of the shift in demographics has been recognised – people living for longer and living with multiple chronic conditions. All of these changes and shifts will have had some effect on the role of the community nurse. However, as none of these changes were instantaneous, there appeared to be no

formal redefinition of the community nurses role. It could be argued therefore that some of the role ambiguity identified by Griffiths et al (2007) originates in the changes made organisational over time.

2.2.1 The Confidence of Community Nurses

Whilst there is research into some specific areas of palliative care provision, the research into the confidence of community nurses is minimal, with studies often just touching on the idea. Community nurse's lack of confidence has been suggested to be one reason for a large number of cancer patients not dying in their preferred place, at home (Simpson, 2003). The nurses are suggested to lack the confidence to provide adequate support for the patient and the family, in part due to insufficient training and time constraints. In reviewing such studies, Rose and Glass (2006) suggest that it is the community nurse's perceived confidence that impacts on their practice. This can be seen in a reflective study with community nurses, considering their experiences, feelings and views on participating in collusion (refraining from discussing the prognosis with a patient on the request of a relative) (Graham et al, 2005). It was found that collusion was entered into by nurses due to a lack of confidence in their own skills. However, despite identifying this, there was no attempt to explore this idea further. Whilst it is certainly important that studies such as these identify that confidence impacts upon the ability of community nurses to provide palliative care, the fact that it has never been taken one step further to consider what it is that increases or decreases confidence means that there is a large gap in the literature.

2.2.2 Stressors in Providing Palliative Care

Although confidence is not a concept that has been considered in detail a number of studies have looked more generally at the experiences of community nurses,

identifying aspects of care that nurses find difficult and cause them stress. The stress experienced by community nurses is a common theme in this area of the literature, with studies identifying that this often stems from a combination of factors (Wilkes and Beale, 2001; Rose and Glass, 2006; Seale, 1992). Isolation was one factor particularly highlighted by Wilkes and Beale (2001). Although their study focused on nurses working in remote conditions not often seen in the UK, their reports of nurses feeling isolated particularly when working alone at weekends and being a long way from support when having to deal with death are not unique in the literature. Butterworth et al (1998) suggest that the very nature of community nursing exposes nurses to a high level of stress as they are literally working behind closed doors. This idea is framed in another way by Luker et al (2000) who see community nursing as invisible work, conducted in the privacy of patient's own homes. They emphasise that this element can cause the work to be highly demanding, both physically and emotionally.

Working with the relatives and family of the person who is dying is a large part of palliative care, particularly in the community when it is these people who often take on the role of primary carer. The importance of supporting this population is highlighted by some authors, suggesting that carers do not always receive the attention that they need (Wright, 2002). This is corroborated by government documents such as the Carer's Strategy (DoH, 2008), setting out short and long term agendas for ensuring that carers are supported and cared for themselves. This is not disputed in the literature; however the experiences of community nurses indicate that working with families and carers can bring its difficulties and can often be a cause of stress to the nurse. As outsiders entering into an emotional situation, it can be the nurses who bear the brunt of the primary carer's stress and frustration, on occasion being on the receiving end of the carer's anger (Wilkes and Beale, 2001). In addition to this, the unrealistic expectations of carers are cited to be another problem that is difficult to resolve. It is acknowledged within Wright's

study (2002), however, that this problem can be eased with the provision of appropriate information to carers. Further than difficulties in working with the carers, there can also be stressors within the wider family. District nurses have suggested that they feel inadequate and helpless in dealing with the children of the patient (Dunne et al, 2005), as well as identifying the difficulties that present when approaching family members in denial (Wilkes and Beale, 2001).

Communication can be seen as a skill that has the potential to bring some solution to many of these difficulties, being a key factor in knowing how to respond to angry and frustrated relatives, or speak to family in denial, or speak to children as they are losing a loved one. It is crucially even more important in ensuring effective support for the palliative patient (Thomas, 2003). Studies however indicate that community nurses are often ineffective in communicating on the difficult issues of death and dying (Wright, 2002). Further than this, as previously stated, nurses have been suggested to lack confidence in this area (Graham et al, 2005). Effective communication requires that there is some understanding of certain skills and knowledge as well as having the opportunity to explore personal and societal attitudes; it is not solely about learning from experience (Wilkinson and Mula, 2003). For this reason authors have recommended that further research and training should go into increasing the communication skills of community nurses (Graham et al, 2005). Thought and care is required in the development of these communication skills (Lawton and Carroll, 2005), and for this reason communication has been identified as a core competency for community workers in NHS Nottingham City (End of Life Competency Framework Pilot, 2009).

In contrast to this, it has been suggested that instead of it being the nurse's lack of knowledge in some aspects of palliative care that lead to difficulties and cause stress, it is rather their lack of control (Seale, 1992). Respondents in this study stated that poor prescribing practices or the lack of knowledge of general

practitioners (GP) resulted in poor pain control for patients that the nurses could do nothing about. It was then the inability to control the patient's pain satisfactorily that caused the nurse's stress. This study was not isolated in identifying GP's as causing difficulties; in a study of urban and rural community nurses in Australia, nurses stated that they didn't feel supported by their GP, for example when requesting that they visit an ill patient (Wilkes and Beale, 2001). Good working relationships between health care professionals are suggested to enable more fruitful work, as well as enabling a more healthy perspective on it (Thomas, 2003). Further than this, collaborative teamwork is associated with better patient outcomes in palliative care (Clough, 2002). Disjointed teamwork therefore can do the opposite, having a great impact on the patient. As an initiative, the Gold Standards Framework helps to establish good lines of communication and good working relationships within the primary care team (Griffin and Sawkins, 2009). For this reason it was introduced into primary care in NHS Nottingham City along with the End of Life Care team in a hope that joined up team work would help to close some of the gaps found currently in the services (Nottingham City Joint Strategic Needs Assessment, 2009).

In a study looking at stress and coping within a population of hospice nurses, McNamara et al (1995) found that personal reactions to death and dying were an area that many nurses found hard to negotiate. These findings were echoed in a study by Seale (1992). However the necessity of confronting their personal thoughts on death was also recognised, being seen as important in order to work effectively with those who are dying (McNamara et al, 1995). The personal values and beliefs of nurses are seen to be intrinsically linked to the good death experiences and further than that, to the emotional journey of the nurse. It therefore becomes essential that they engage with these personal thoughts in order to provide the best care as well as avoiding burn out (Evans and Walsh, 2002).

It is important to consider here that the literature does indicate a high degree of job satisfaction amongst this population, despite the level of stress experienced. Nurses have stated that they find palliative care satisfying and experience positive feelings in addition to negative feelings in respect to this area of their job (Dunne et al, 2005; Rose and Glass, 2006). Although many studies focus on the stresses experienced, there are clearly elements of the role that motivate nurses to continue providing this care.

2.3   **Training and Education**

It has been suggested by those looking at how community nurses cope that too much emphasis has been put on training and education (Hopkinson et al, 2005). However since it has been identified that a main stressor for community nurses are educational deficits (Rose and Glass, 2006), it would seem that there is a need for more of this than is currently available and accessed. Specifically mentioned by community nurses are knowledge deficits in pain management and symptom control (Dunne et al, 2005). Difficulties in controlling pain and symptoms have been seen to trigger unnecessary referrals to the specialist and MacMillan services (Aitken, 2006). Whilst the MacMillan Nurses, with their extended knowledge, are a useful resource, it can be suggested that the community nurse's lack of knowledge leads to a lack of confidence, therefore impacting on the nurse's ability to support the patient appropriately (Simpson, 2003; Dunne et al, 2005).

Government policy also recognises that there is a need to ensure that community nurses have adequate knowledge to provide quality care. As palliative care has begun to move towards being a discipline of its own, the Department of Health (DoH) and other leading bodies have acted to bring national standards to the care given. The End of Life Care Strategy (DoH, 2008) is the most recent of these. With regard to the health care professionals providing the care, it highlights that

the highest possible levels of nursing knowledge, skills and attitudes are required to be able to give quality care to those that need it. It proposes that this is achieved by ensuring that competencies are reached by pre-registration nurses and other health professionals. It also suggests that post-registration, there should be wide-reaching continued learning courses available and appropriate appraisals of staff competence. A similar outline is also presented by the Royal College of Nursing (2002).

However, these recommendations do seem to echo those made in The NHS Cancer Plan eight years before (DoH, 2000). Although specifically addressing the issues of cancer services, this framework recognised the need for district nurses to receive further training in the areas of cancer and end of life care. From the recommendations made, money was set aside by the government for training purposes, and this was said to reach over 15,000 community nurses and healthcare professionals (DoH, 2008). The End of Life Care Strategy states however that despite this push, there are still many community nurses who have received little or no post-registration education in this area (DoH, 2008). Locally it proved difficult to obtain evidence of the implementation of these strategies. However the End of Life Care team, a newly implemented initiative, have been introducing a pilot competency program for the primary care team (NHS Nottingham City, 2010).

2.4   Support

Within the population of those caring for the dying, psychological and physical morbidity is high (Thomas, 2003). This can be attributed to the highly demanding work that is required, both physically and emotionally. Although not found directly within this body of nursing research, Hochschild's (1983) concept of emotional labour does bear some relevance to the provision of palliative care in the community. Hochschild proposes that many jobs require something more than

simply physical or mental labour; that is emotional labour. Essentially this is a job necessitating "one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others" (Hochschild, 1983). This slightly abstract definition is explained through the example of an airline stewardess, who is required by her role as hostess on the aeroplane to smile and present herself, and therefore the company, as cheerful. However, this in itself isn't the emotional labour. The emotional labour is instead the way in which she has to disguise her personal irritation or fatigue in a way that doesn't show the effort it requires.

For all nurses working in any area of health care, it is often called for them to provide care whilst masking their inner feelings (Bishop, 2007). The emotional labour is required to ensure that the patient and relatives do not recognise this. Further than this, in the area of palliative care, nurses are expected to provide emotionally for patients often at great cost to themselves (James, 1992). Whilst in a hospital there is support for nurses immediately surrounding them; it takes the maintenance of a strong support network in the community, which should also be facilitated within the work environment to avoid exhaustion and burnout (McNamara et al, 1995).

It is recognised how highly demanding this work is on the nurses providing the care, and for this reason, hospital management are increasingly aware of the need to support their staff (McNamara et al, 1995). Hopkinson et al (2005), instead of focussing on how training and education can provide support, theorise that when caring for dying patients, nurses build for themselves a web of support. In developing this framework, their hope is to demonstrate that there is no one way that nurses cope; instead a range of different mechanisms are utilised. Aside from this theory, the opportunity to debrief stress and discuss difficult situations is seen as crucial to the wellbeing of the nurse (Wilkes and Beale, 2005). Educational

sessions are also suggested as being important within a network of support (Wilkes and Beale, 2005). Team work again is stated by many as crucial in creating a supportive environment (McNamara et al, 1995). This can be as simple as talking experiences over with a colleague (McNamara et al, 1995), or alternatively the actions of a team leader to create a healthy, no-blame team culture that encourages honesty and openness (Thomas, 2003). It has been suggested that many of these strategies are available informally for nurses, but there is a lack of a more formalised framework for support (Hopkinson et al, 2005).   Clinical supervision is a more formal strategy that has developed on the national agenda as a means for nurses and other health care professionals to evaluate their practice personally, as well as having a place to access professional support when needed. It is seen particularly to be of use within palliative care for helping nurses as they face death regularly (Bishop, 2007).

2.5   Chapter Conclusion

From the literature considered, it is clear that caring for dying patients can be highly stressful and places considerable demands on community nurses. There are a number of studies that suggest that the stressors and difficulties experienced are significant and experienced by many community nurses, and that these stressors do impact upon confidence and ability to provide care. There appears to be a clear gap in the literature considering the confidence of community nurses in providing palliative care. Further than this, despite the government policies indicating change in how community nurses are trained and supported, it was not possible to find any literature specifically on the support networks available. This study therefore aims to play a part in filling this gap, looking at the confidence of community nurses in providing palliative care and the training and support available to them.

Chapter Three

Methodology

3.1   Chapter Introduction

My interest in investigating the confidence of community nurses' in providing palliative care arose from working alongside community nurses on placement, observing them in this role and talking to them about their perceptions of the work. From this, my research question developed. Before looking at the experiences of community nurses however, it is important to consider the theory that underlies all research. From a nursing perspective, this is an area that is often neglected: put aside either as irrelevant, considered only for a label to the study or mentioned only in relation to technique and procedures (Koch, 1995; Simmons, 1995). Although delving to the depths of the philosophical underpinnings of methodologies is beyond this dissertation, a foundation of understanding will be helpful to the research process. As Silverman states 'Theory…should be neither a status symbol nor an optional extra in a research study. Without theory, research is impossibly narrow. Without research, theory is a mere armchair contemplation' (2005, pg 107).

This chapter will begin with a discussion of the philosophical assumptions that underlie the various methods used in nursing research, identifying where this study sits within them. There will then be discussion of the practical elements of the study, detailing how the research study was undertaken.

3.2   Philosophical Assumptions

Research questions generally have a predisposition towards being studied using either quantitative or qualitative methods. Whilst the research question does guide the decision of research design, it is argued that the researcher's philosophical perspective will influence the generation of the question and the type of question asked, which will then point towards a research method (Bryman, 2004; Koch, 1995). Two major philosophical perspectives will be considered here, as this will

help to understand why the research methods were chosen. It is important to recognise here that the terms quantitative and qualitative can and will be used to refer to both epistemological (the foundations of knowledge) issues and practical issues (Bryman, 2004).

The quantitative paradigm arises predominately from positivist principles, the belief that reality exists independent of human observation and it can be known and studied (Porter, 2000). Positivism can be included within the sphere of philosophical objectivity, defined as, the 'conviction that there is…some permanent a-historical matrix or framework to which we can ultimately appeal in determining the nature of rationality, knowledge, truth, reality, goodness, or rightness' (Bernstein, 1982, in May, 2001). It is considered that these facts, this framework, these objective truths can be uncovered, and 'science' is held up as the means to identify them (Trigg, 1985). Quantitative research developed in an attempt to identify objective truths through the rigorous formulation and testing of hypotheses. Positivists believe that both the natural world and the social world can be studied using these principles; however clearly the social world is intricately more complex than the natural world due to people having the capacity to think, reason and use free choice (Gerrish and Lacey, 2006). Positivism therefore seeks to explain human and societal behaviours in terms of cause and effect, seeing social interaction as simply the collision of physical objects (May, 2001; Trigg, 1985). In this way, humans can be studied using the same scientific methods as the natural world (Topping, 2006).

A strength of quantitative research is that it generates data under rigorous sampling controls and thus is seen to be free from subjective interpretation (Polit and Beck, 2010). It also produces large amounts of information in relatively short amounts of time due to the methods employed, for example surveys, questionnaires and randomised controlled trials. However, quantitative research

does not answer all questions appropriately. Nursing research often focuses on people and their experiences, both complex and diverse phenomena and these complexities cannot always be reduced to measurable results (Polit and Beck, 2010). Furthermore, although its objectivity can be seen as strength, it can be questioned to what degree this objectivity can even be obtained. Is it possible for a researcher to become objective; surely even the most experienced researcher remains as much part of society as they are a researcher and cannot truly suspend this or their values (May, 2001). It can also be asked if it is possible to study matters of society through objectification and scientific methods and if so, if it is even desirable to do this.

Those who ask these questions may look towards the qualitative paradigm for their answers. This originates from a naturalistic viewpoint and acknowledges that although there may be external realities, there is no way to know these objectively (Dodd, 2008). The social sciences subscribe to this perspective, proposing that all we can know for certain is from people's interpretations and perceptions of that reality (Porter, 2000). Human behaviour is not seen as cause and effect, instead there is more emphasis on humans having depth and the ability to shape their experiences (May, 2001). This understanding of knowledge has meant that qualitative research has moved away from the quantitative methods of rigorously developing and testing a hypothesis. Instead it tends to utilise methods that yield in-depth data revealing the many dimensions of experiences. It is commonly understood that qualitative research methods are more flexible (Clissett, 2008), allowing researchers to follow lines of enquiry that present themselves throughout the research.

These things make qualitative research methods ideal for nursing research which largely surrounds the experiences of patients and healthcare professionals. However, qualitative research is also not useful in answering all research questions,

as some questions require measurable results. The subjectivity that is the strength of qualitative research can also be a limiting factor if it is not turned to the researcher's advantage. The researcher themselves, as the tool of data collection, will bring their own perspectives and narrative into the data collected (Porter, 2000); however this is something that should be utilised and exploited rather than removed. The small sample size and the often specific nature of the population being studied mean that it is not possible to generalise the findings to a wider population. However, it is possible to build theory from the findings of qualitative research and this theory may have applications wider than the specific findings themselves (Bryman, 2004).

To return to the start of this chapter, the reason behind the research question was an interest in the confidence and experiences of community nurses. This study therefore clearly leans towards the use of qualitative research methods. This also reflects the researcher's current understanding of knowledge, seeking to find meaning through people's experiences, rather than attempting to identify objective truths behind them.

3.3   **The Research Methodology**

Research methodologies have developed as researchers holding varying philosophical stances have undertaken research in ways consistent with their underlying assumptions.   For example, applied philosophy underlies phenomenology and grounded theory has its roots in symbolic interactionism (Holloway and Todres, 2006; Morse and Field, 1995). These methodologies are therefore, a means of using philosophical assumptions to inform the research process. This study, with an aim of exploring how confident community nurses are and their experiences of providing palliative care, will predominately utilise a

phenomenological methodology. However, ideas drawn from grounded theory will also be used.

Phenomenology is the study of phenomena - the events, situations, experiences or concepts as they appear through our experiences. Historically, the research tradition is attributed to Husserl, who felt that explaining human experiences from an external viewpoint was not adequate (Dowling, 2007). He therefore drew ideas from early philosophers who viewed subjective human experiences as a valid starting point for philosophy (Sawicki, 2005). From this perspective, Husserl could use subjective experiences to gain understanding of phenomena (Todres and Holloway, 2006). Through re-examining the experience of phenomena, he attempted to create an objective description of it; to uncover insights that could be applied more generally beyond the cases studied (Todres and Holloway, 2006). Heidegger sought to develop Husserl's descriptive phenomenology, however he moved away from Husserl's positivist leanings as he did not agree that there could be objective description of lived experiences (Dowling, 2007). Instead, Heidegger believed that meaning could only be found in the interpretation of the phenomena by a person (Fay, 1996). Phenomenological studies therefore rely on the recollection and descriptions of experiences by participants, and their understandings of the phenomena in question.

The research question for this study leans towards phenomenology, quite simply because it seeks to describe, interpret and understand the experiences of community nurses. Heidegger's interpretive perspective will be used, largely because as a researcher, I believe that no description to be free from interpretation. For these reasons, the research process will draw from an interpretive phenomenological methodology.

However, in addition to this, grounded theory can input some valuable methodological contributions to this study. As a methodology, it starts with the assumption that all people make sense of and order their world, even though it doesn't always appear this way to outsiders. Those who share common circumstances also share common perceptions, beliefs and behaviours but these understandings may not always be articulated; grounded theory therefore seeks to identify these (McCann and Clark, 2003). The theory that is built is seen to be grounded fully in the data gathered, that is it is inductive, no initial hypothesis is being tested (Speziale and Carpenter, 2007). The question for this current study arose from observations made in practice and the aim is to explore these observations further. No hypothesis has been formed, and therefore it will be inductive. Grounded theory also utilises the technique of "constant comparative analysis". This involves the simultaneous collection and analysis of data, with the ideas that emerge being used to guide the subsequent data collection (Hancock, 2000). This idea will also be used within this study, as it will ensure that when the conclusions of the study are reached, they will be firmly grounded in the data.

3.4   **The Research Methods**

3.4.1 **Setting**

The research site for this study was a large city wide National Health Service Primary Care Trust (NHS PCT) in the East Midlands. Participants were recruited from six health centres across the PCT. The interviews were undertaken at the health centre at which the participant was based during the autumn of 2009.

3.4.2 <u>Access and Ethics</u>

In order to undertake research within the NHS, there are a number of 'gatekeepers' from whom it is necessary to gain permission prior to the start of a research study (Benton and Cormack, 2000). These processes are in place to ensure that all research undertaken within the NHS meets high standards, to protect, respect and maintain the autonomy all NHS patients, data, staff or facilities (DoH, 2005).

For this study, the gatekeepers were identified as being the Local Research Ethics Committee (LREC), the local NHS Research and Development (R&D) committee and the District Nursing (DN) Head of Service. The study was deemed ethically sound initially by the LREC, following an interview with the committee (Appendix One). Following this, permission was sought from the local Trust R&D team, who agreed that the study could be undertaken within the Trust (Appendix Two). Permission was also gained from the DN Head of Service to recruit community nurses within the Trust.

The following issues were judged to be of importance for this study and therefore addressed within its design.

Informed Consent

Informed consent indicates that "the participants have adequate information regarding the research, comprehend the information and have the power of free choice, enabling them to consent to or decline participation voluntarily" (Polit and Beck, 2010 p.127). For this study, a Participant Information Sheet was produced providing all the information required for an informed choice to be made (Appendix Five). Prior to the start of the interview a consent form was signed by each participant stating that they agree to take part in the interview and for their contributions to be used in this dissertation (Appendix Six).

Confidentiality

Participants were informed prior to the interview that the experiences that they shared would remain confidential. This was done by making the data anonymous during the transcription process and removing any material from which the participant or their patients could be identified. Identification numbers were substituted for names on the study records. In the process of publicly reporting the results of the study, no real names were used and no key characteristics of participants were identified. During the study, any participant identifiable material was kept secure, including digital recordings and consent forms, and was only accessed by the researcher and the researcher's supervisor. At the conclusion of the study, raw data and the study records will be kept secure as per the university policy.

3.4.3 Contact and Recruitment

Participants were identified for this study using a purposive sample, selecting nurses who work within the community with patients requiring palliative care. Using a purposive sample ensures that those individuals who partake in the study have experience of the subject area and are able to articulate their lived experience of that subject (Polit and Beck, 2010).

Following permission from the DN Head of Service, contact was made with the nurses managing teams within the trust. Having identified that the correct approvals were in place, they were indispensible in contacting the Community Nursing team leaders (Appendix Three). The ethics board stipulates that contact should be made with potential participants indirectly to prevent any pressure or coercion influencing the decision to take part. The team leader in each health centre therefore distributed the letters and information about the study to those

nurses who were working within the community and had cared for at least one palliative patient in the last year (Appendix Four).   In total, 29 letters were distributed to nurses in six health centres. Nurses interested replied to the letters and were contacted directly to arrange an interview.   Thirteen nurses replied positively and were contacted by the researcher. One was unable to be contacted, so twelve interviews were arranged. Of the arranged interviews, two participants did not attend. Therefore the study consisted of ten interviews with community nurses from five health centres.

3.4.4 **Reflexivity**

Within qualitative research, it is seen to be impossible to remove the researcher from the findings of the study; that is they are implicated in how the findings have been constructed, in how they have observed, processed and conveyed the findings of the research (Bryman, 2004).   Within this study, it is seen as essential to recognise this and engage with it. This entails a researcher being reflexive, aware of their cultural, political and social background and how this impacts the research. Two factors of particular interest for this study would be that the researcher is a student nurse, within 6 months of qualifying as a registered nurse.

3.4.5 **The Interviews**

The interviews were carried out using an semi-structured interview technique, allowing participants to put into their own words their experiences and to express the elements of the experience that were relevant to them (Pontin, 2000).   An interview guide (Appendix Six) was produced as a prompt for the areas to be covered by researcher within the interview, as well as a requirement for the ethics committee.   The use of this guide by no means led the interview however, as it

simply listed sample questions of the areas to be covered; the exact wording and order of the questions was determined in the interview.

The initial questions asked were designed to set the scene for the interview and to build rapport with the participant. Building rapport is seen to encourage openness on the part of the participant (Speziale and Carpenter, 2007). These questions also helped to gather contextual information about the participant, such as how long they had been nursing in the community. This information added into the bigger picture of their experiences of palliative care. Later into the interview open-ended questions were favoured and a conversational tone adopted to allow the participants to verbalise their experiences freely (Morse and Field, 1995). When unanticipated topics arose, these were followed through with prompting questions. The interviews ended by giving the participant the opportunity to cover any area of importance not yet spoken about. They lasted between twenty minutes to forty-five minutes, with none exceeding this time largely due to the time constraints of the community nurses being interviewed.

The interviews were digitally recorded to allow full concentration on the participant and their responses during the interview, as well as detailed analysis of the data afterwards (Morse and Field, 1995; Pontin, 2000). Alongside the recording, notes were taken throughout the interview, ranging from observations of the participant to any initial analytical thoughts. These notes formed the basis for a reflective memo written following the interview. In two interviews, the recording device failed, so time was spent immediately after the interview recalling what was said. In these cases, the recollections and the notes from the interview formed the data collected. The eight recorded interviews were fully transcribed for analysis.

3.4.6 <u>Data Analysis</u>

The analysis of qualitative data is labour-intensive and requires the researcher to fully immerse themselves into the data, but more than this it requires creativity in fitting data together whilst ensuring that the uniqueness of each persons lived experiences is retained (Morse and Field, 1995; Polit and Beck, 2010; Speziale and Carpenter, 2007). Giorgi's framework of analysis (1985, in Todres and Holloway, 2006) was used in this study as follows:

- o The entire transcript was read to get a sense of the text as a whole.
- o The text was divided into significant phrases and statements, which were then expressed in more transferable and general ways.
- o These expressions were grouped into themes, and then theme clusters.
- o Bringing these theme clusters together into wider theme categories provided the basis for the findings chapter of this dissertation, and subsequently the discussion.

3.4.7 <u>Quality</u>

Within qualitative research, the principles used to generate high quality data are credibility, dependability, confirmability and transferability (Lincoln and Guba, 1985, in Morse and Field, 1995). These terms however have arisen from similar ideas used in quantitative research to ensure its reliability and have since been adapted to build rigor into qualitative research. It can be argued though, that since qualitative research arises from a different perspective to quantitative research, a meticulous adherence to these principles has little place in this study. However, despite the reaction that some qualitative researchers have to these principles, there is still a need to be able to judge qualitative research of sufficient quality to contribute to wider understanding, particularly in nursing where this is clinical

practice. Speziale and Carpenter (2007) suggest that an audit trail can provide this. Activities, evidence and thought processes over the study period are recorded. This trail helps to keep the process transparent, allowing observers to see clearly how the conclusions to the study were reached. A reflective diary was kept throughout the research process, keeping note of what happened when, and how it impacted on the researcher and the research process. As well as being a place to be reflexive and reflect, this also became part of the audit trail for the study.

3.5   **Chapter Conclusion**

This chapter, beginning with a discussion on the philosophical assumptions of research, identifying that phenomenology provided a foundation for the study, whilst using some ideas from grounded theory. The process of carrying out the research was then discussed in depth, outlining the preparation, the interviews and the analysis stages.

Chapter Four

Research Findings

4.1   Chapter Introduction

This chapter contains the results of the data analysis carried out on the interview transcripts. Each category reported was built from theme clusters which have been included in the reporting of the findings to help bring some order to the ideas described by the participants (table 1). In order to ensure that the uniqueness of each participant's experiences is also presented, some of the significant phrases from participants are included within each category. Since there are overlaps in the themes, these will be commented upon in each section.

Theme Category	Theme Cluster
Confidence	
Providing palliative care	- Specific aspects of care
	- For nurses new to community
	- Personality
Experience	- Recalled nursing experiences
	- Life experiences
	- Amount of experience
Training	- Palliative care in nurse training
	- Opportunities for training when in the community
Support	- Community Nursing Team
	- Clinical supervision
	- Coping

Table 2 - Theme Categories and Theme Clusters

4.2   Participant Demographics

All the participants in this study were female, from 29 to 56 years old. Participants with different amounts of experience were interviewed, including four who had been

a community nurse for less than five years; one of these was newly qualified and three had some previous nursing experience. Six participants had been a community nurse for between five and 27 years. Of the nurses interviewed six were Community Nurses, and four were District Nurses, one District Nurse was also a community nursing team leader. Two of those interviewed were Palliative Care Link Nurses and one nurse interviewed was a District Nursing Practice Teacher.

4.3   Confidence

As the over-riding theme of this study, confidence enters each of the four following sections. In general however, all of the participants identified the extent of their confidence in providing palliative care - eight participants stated they were confident, whilst two stated they were not. All went on to speak of confidence further, considering specific areas of high or low confidence. They also spoke of how a lack of confidence has the potential to impact negatively upon practice, an idea considered in the section on experience. All of the participants agreed that it was possible to increase confidence, with those experienced participants speaking of how this had happened and those new to the community speaking of how they saw it was possible to do so.

4.4   Providing Palliative Care

This category contains a wide range of ideas, some of them touched on by only one or two participants. However the decision to include them has been made because they all relate to the confidence of the participant describing them.   They demonstrate the range of skills needed to work as a nurse in the community and the diversity of situations and people encountered. These are important themes to consider therefore, since palliative care is one of the four main areas of the community nurses work load.

4.4.1 Specific Aspects of Care and Working in the Community

Two of the participants stated that a primary reason for joining the community nursing team was to spend more time with patients, working for their individual needs. This appeared to be of particular importance with the palliative patients, as much of the work that is done involves supporting the patient before they reach the end stages of life. Since this commonly involves psychological support, it needs to be built on a relationship, as the issues being discussed can be very emotive:

> *You've got to build up a relationship with people, they're not just going to tell you about their…death sentence if you rush in and out.*
> P3

However, it was here that some stress and frustration was obvious for some of the participants. All the participants agreed that palliative patients took more time than other visits, and that often other patients would be put aside in order for those visits to be made. With that, and the current drive to have more patients dying at home, two of the participants specifically indicated that they were stretched for time, particularly at weekends and therefore not able to give the quality of care they desired, causing dissatisfaction. The participants who had more recently entered the community spoke more positively about having adequate time to visit patients whilst the participants who had more experience or were in a position of team leadership indicated frustration at not having the time to provide the care they wanted to give.

Adding to the issue of time was the fact that at the end of life, when a patient was on a syringe driver, each visit required two nurses. This clearly added pressure in terms of time management for some of the participants, although for two it was seen as being positive as it meant they were not alone. Whilst participant 6 clearly

stated that she never felt alone in the community, two participants disagreed with this, suggesting that it was possible to feel very isolated:

> *You are working on your own…I know you've got mobile phones and you can ring somebody…but I think that's quite a difficult thing…when you realise…"its only me here."* P9

One area where two of the participants felt particularly confident was in the practical aspects of care. However, this was the only specific area that participants identified as being confident in. More commonly mentioned were areas in which they lacked confidence. One such area was communication about death and dying. As a theme, this recurred numerous times, with participants identifying that much of a nurse's ability to provide palliative care rested on these skills:

> *It all boils down to communication. Good communication and you're fine*. P6

Having stated this however, only two participants specified that they were confident in communication. The others who mentioned it spoke more speculatively on how confident in this area helped. One participant stated that her lack of confidence caused her a great deal of apprehension:

> *I've had some situations where…somebody's asked me a question…like "am I dying" and I've found that really hard, you know, you're so frightened to say the wrong thing*. P5

Three participants suggested that one element of being confident in communicating with a dying patient was being comfortable with the issues of death and dying, an idea picked up again in personality. An area of particularly difficulty that

participants both experienced and inexperienced spoke of was of knowing how to communicate with a patient in denial. Two participants stated that despite their experience and knowledge in the area, this remained a difficult area to negotiate. This, and difficulty in talking about death, were suggested at times to lead to avoidance, with three participants identifying that they have seen nurses avoid the issues that they do not feel comfortable talking about. This was suggested to ultimately cause more distress and a lack of trust between the patient and the nurse.

Interaction with family members was recognised to require specific communication skills and appeared to be a particular area of difficulty for four participants. Largely however, despite the challenges, many of the participants did also say that there could be huge positives to working with families, particularly when they were very supportive and helpful:

> *It also puts different personalities in the mix, its not always about*
> *one person, it's often a few and they all have different personalities*
> *and ways of coping.* P4

> *This family…cos they were so big and they stood out cos they were*
> *always there, for the wife who was losing her husband.* P2

As a final specific area of palliative care that five participants identified as finding difficult, was the relationship with the GP's. All of these five participants stated that they had experienced difficulty in working with GPs on various issues. In itself this was not always problematic, although it certainly made the job of the participants more difficult. However, it became a problem for one participant:

The thing that gave me confidence in palliative care…was the GP's

because they were brilliant…but that's not the case here. P5

Of course, important to note here is that some participants did also comment on the support that their GP's were to them in caring for palliative patients.

4.4.2 Nurses New to Community

A large proportion of the participants spoke of nurses entering the community for the first time and how different it is providing palliative care in this setting. The best way to adjust to these differences was proposed to be time and adequate support. It was suggested repeatedly that this could be partly achieved through mentoring and visiting palliative patients in pairs. Two participants mentioned that recognising how heavy the expectations placed on nurses entering the community, by themselves, by other members of staff or by patients are, creating unnecessary pressure. Participants stated that part of this was a feeling of being 'dropped in at the deep end'. One participant however indicated that this wasn't necessarily a bad thing, likening it to learning to drive – lessons and a test are taken and if passed, the driver is deemed to be safe. However it is only once alone in the car that the driver truly learns. Similarly with nursing, both entering as a newly qualified nurse or into a new job, training can be given and a nurse can be deemed to be safe to practice. However it is only once they are working alone that they will truly learn. At some point, they have to be 'dropped in the deep end'. Situations however won't always go as planned, and participant 1 voices her opinion that in these situations, it's important not to undermine the confidence of other nurses:

It makes me cringe…when I see people undermined…you

don't have to say "oh, I told you that before," you could

prompt someone to say "oh, I did mention before about…"

cos there is so much to remember isn't there. P1

As is reported in the experience category, the way in which nurses are introduced to palliative care and how experiences are debriefed with them, is important for the confidence of these nurses in the future.

4.4.3 Personality

Personality is a slightly abstract theme to fit into the providing palliative care section and certainly enters the other categories discussed; however many of the participants mentioned it as a factor that impacted their ability to care for dying patients. As mentioned, many participants stated that communication was an area of difficulty for them. Those who did not have a problem with the communication side of care indicated that this was largely down to their personality:

I feel comfortable with patients that are dying, and I think that in itself is important. P3

I suppose I'm not one who's frightened to talk about feelings. P5

The overriding idea that came out when participants were discussing personality was that palliative care was not something that everyone could do or would want to do, that often the ability and confidence to provide aspects of palliative care would be influenced by an individual's personality.

Within this category, the participants spoke of issues that they come across as they provide palliative care: some in which they felt confident and others in which they

did not. However, it was suggested that a lack of confidence in some areas does not mean a lack of confidence in every area. An overall impression gained from the participants was that the role itself was a stressful one, added to by the pressure created by the finality of the situation:

You can go in on some situations and just feel completely out of your depth, even if you've started to feel confident. But that doesn't take the confidence away for next time you go somewhere else. P10

I always think that that you can't change the situation, it's not like a wound…its different. P1

Many of the participants held this same view, with two stating a desire to provide perfect care for patients in their final days, finding it difficult when it was not possible to do this. Participants did suggest however that it was essential to maintain perspective and recognise their own limits.

4.5   Experience

Experience was spoken about in many contexts, but most significantly were how experiences have impacted upon confidence, how life experiences affect this and how the amount of experience had impacts upon the provision of care.

4.5.1 Recalled Experiences of Palliative Care

All the participants recalled specific experiences of providing palliative care, although it varied significantly whether this was a positive or a negative experience. The participants in most cases went on to state what impact these experiences had had on their confidence. Good experiences were felt to have a positive impact on

the participant, whilst negative experiences were seen to have a number of possible outcomes, related to how they were processed or dealt with following the experience. Participant 1 recognised that mistakes can be made and reflection is necessary, but it needs to be done positively and purposefully. Another participant however found it difficult, having reflected, to know what the next step was:

> …*things like that, you sort of feel, not good cos someone's died, but you sort of feel that you've helped that be a better situation.* P4

> …*I don't analyse it every detail. Cos I think for self preservation you can't…it would do your head in…but I do look back and think on reflection I could have got that better*. P1

> *I mean it did I suppose at the time make me think, how can I stop that happening again…I don't really know if there is an answer to that.* P2

It was suggested that negative experiences could have a lasting impact on nurses. One experience recounted by participant 4 indicated that her confidence had been knocked by a negative experience as a student, and that this continued to have an effect:

> … *if they have a bad experience initially, that could have a knock on effect…we don't always get it right but…you don't want your confidence knocked because you may avoid even more then*. P3

> …*that has bred a lot of my insecurities because a lot of the time I'm thinking have I put my foot in it, have I said the wrong thing…* P4

The experiences of palliative care encountered by the participants were obviously influential on their confidence and how they felt about their ability to provide care in the future. It was identified by participant 2 however that debriefing wasn't available formally in difficult situations. Other participants recognised that this role was filled by the community nursing team. This theme is considered more in the section on support.

4.5.2 Life Experiences

Personal experiences of death were suggested by five participants to play a central role in increasing their personal confidence. This was attributed to understanding what needs to be said and when, as well as an appreciation of the of the primary carer's work. One participant was careful to state the following however:

> *I'm not saying just because I had my parents die that other nurses can't, don't understand. I just feel in my case…that that's helped me.* P9

Other life experiences were also mentioned; participant 5 identified that her experiences of group counselling following her divorce gave her understanding of what it is like to sit and talk about feelings. Two other participants also recognised that there are many phases of life that increase a nurse's ability to care:

> *…the things that you experience in yourself…well they make you more empathetic towards what people are going through really.* P5

It was suggested by participant 5 that a primary factor is age; that her perspective has changed as she has walked through life. Further than this participant 9

recognises that as she has got older she has become more able to recognise and admit her weaknesses whilst still growing in confidence:

> *I think I'm more open to accept that I need that help…I mean when I was younger…I thought I knew, well not knew everything, but I thought that I could deal with everything on my own.* P9

Three participants commented that life experiences made it easier to relate to and empathise with patients. However they also added the difficulty of becoming emotionally involved. On the whole though, despite this, participants did suggest that being able to relate to patients was beneficial:

> *Sometimes you do get…involved… there is a 23 year old at the minute. I've got a [teenage] daughter, and you know… I walk in there and my heart flips*. P1

> *Basically I think if you go in and you tret them the way that you would like to be tret if you was in that situation, or if it was a member of your close family...you can't go wrong*. P6

4.5.3 Amount of Experience

The area most frequently referred to on the theme of experience was the participant's amount of experience and the impact of this on confidence. Experience of caring for dying patients was recognised by participant 2 to be the best way to learn:

> *You can…know the facts but until you're put in the situation you don't get the confidence in dealing with the real life.* P2

Of the participants who stated that they were confident in providing palliative care, many said that they had lots of experience in the area. For those who stated they had little experience, it came across as a hindrance and as a factor impacting their confidence. Participant 2 suggested that due to her inexperience in the area, she was rarely sent to palliative patients, with the effect that she was unable to build up her confidence. Similarly, participant 5 stated that she was often given the majority of palliative care patients due to t lack of confidence of other community nurses.

Participant 2 also indicated that she felt inferior to those who had been working a longer period of time to her. This opinion however wasn't shared by any other participants; in fact participant 6 stated the opposite:

> *I think…cos I'm working with people who've been in the job a lot longer even if I did go regularly into [palliative patients] they'd always be kind of so much more knowledgeable.* P2

> *I've been in the community 8 weeks…and I've been fine…I haven't felt worried, I haven't felt that I lack the experience to go in.* P6

Again within this section it is highlighted how closely linked the themes are. The emerging themes of the amount of experiences had and what those experiences were, appear to be significant in defining the way the participants view themselves, their confidence and their ability to care.

4.6   <u>Training</u>

This was a theme commented on significantly by many of the participants, particularly on how it prepared them to carry out palliative care.

4.6.1 Palliative Care in Nurse Training

The participants found it difficult to recall what teaching they received on palliative care within their pre-registration training; the general consensus was that there was not a lot. The participants agreed that their introduction to palliative care was when on placement, but that this entirely depended on where they were for these placements. This variation meant that some of the participants had experienced very little death and palliative care when they qualified, whilst others had a vast amount of experience. It was suggested that there should be more exposure to care of the dying, but then recognised that practically that would be difficult due to the lack of dedicated hospice beds:

> *I met with very little death in my training…whereas some of my friends that I trained with, they'd go "another cardiac arrest…" and you think "I haven't seen any like that.* P10

The other aspect of learning about palliative care that was implied but not voiced explicitly was how experiences of palliative care as a student were processed or debriefed. Many of the participants recalled that as students, when they experienced death, none of the staff talked to them about it and that they were just expected to get on with it. A few of the participants mentioned that now they have become mentors, they are careful to debrief situations with students; whether this was a personal thing or a change in how student nurses are supported within their training was not indicated.

I can still tell you my first death on the ward…I can remember going home on the bus and absolutely sobbing all the way home…and nobody ever talked to me after about that. P4

4.6.2 Opportunities for Training when Entering the Community

There were mixed comments on the training available for nurses on entering the community, with some participants having completed lots of training, whilst others had received little. The overall picture was that some competency courses were required for nurses to be able to provide certain aspects of care, for example in the use of syringe drivers. Aside from this many of the nurses stated that they had attended a five day introduction course at the local hospice. There was however variation over when this was attended. Neither of the two participants who had been qualified for less than two years and were new to the community had attended the five day training course at the time of the interview. Both indicated that they would appreciate the input in the area of palliative care:

As soon as I started, I think I was put on to do the five day course. P9

Probably two or three years after I started in community I went and did the five day palliative care course. P5

Although it appeared that the course was aimed at introducing the multi-faceted nature of providing palliative care in the community, one participant indicated that she was only put onto the five day course once she had shown further interest in the area. It was noted by two others that the people who need the general training were not the ones being sent on it:

Initially if there was some training that might have been more helpful than sort of like picking it up as you go along and then doing more training when you feel confident enough to do the training…really you should be going when you feel like "I don't know what I'm doing". P10

The only other course mentioned was a communication course run by the local hospice. This focused on using the experiences of those attending to learn new and different ways of approaching difficult situations in communication. Both of the two courses received high reviews from the participants who had attended them, all agreeing that they were beneficial to them and their work with palliative patients. Participant 1 however, whilst agreeing the training was of a high quality, believed that it would be more appropriate coming from those who work in the community with patients at home; stating that the hospice nurses, whilst having great expertise in palliative care, do not understand some of the difficulties encountered when caring for patients at home. Continued learning courses were suggested by participants 9 and 10 to be more beneficial in building on practice and previous knowledge:

They used to do very good sessions about once a month…on different aspects of palliative care and…doctors, nurses…the social side…relatives, would do sessions. And they'd all be very, very informative. P10

Whilst recognising that training is important, participant 7 indicated that it is possible to receive a lot of preparation and still not be ready. She suggested therefore that training is not in itself sufficient preparation, that it only plays a part in the growth of confidence.

Within this section, training is given mixed reviews, whilst what was available was adequate, it was always received at an appropriate time or by the right people. It was also suggested that training by itself would not have a significant impact on confidence.

4.7   **Support**

All of the participants stated or implied that providing palliative care could be tough and draining, and therefore the support available was of great importance. It appeared that access to, or indeed the lack of access, could be the defining point in how they were able to provide care.

4.7.1 Community Nursing Team

The participants all agreed on the fact that their community nursing team was the main place of support. This did not occur in a formal way, but more during times of the patient handover or when sitting working in the office. It appeared that this team support performed a number of functions, from being the people to whom it is possible to vent frustrations, to using them as a sounding board when uncertain about a course of action. This idea of using the team's collective knowledge and learning from other team members was repeated by half of the participants as being significant. Three participants suggested that being able to say "I don't know" and ask for help removed some of the weight of expectation from them:

> *Just ask…if you're not 100% confident, ask somebody with that experience, and they're happy to do, and they will mentor ya through it.* P6

That helps the confidence…knowing that you're not expected to know

the answer to everything. P10

The palliative care link nurse was seen to be a helpful role within the team, someone to provide specific advice and directing participants to further resources. A supportive team was suggested to share the patient load between the whole team without one nurse taking on all the palliative patients. This was seen to be particularly important if a member of the team had experienced a personal loss or had had a difficult experience with palliative care.

Four participants stated that team leadership indirectly impacted all these things, being central to how a team works together. Particular important was that a team leader was an approachable, supportive person themselves, therefore creating a team environment with the same characteristics. Beyond this, an empowering team leader was seen to be important:

Even as enthusiastic as I am…if I worked with somebody…that wasn't

motivated and interested and allowed me to lead it, I could see there

a lot of frustration that would come. I would be held back. P6

As a team leader, participant 8 spoke of giving the nurses under her leadership permission to find situations difficult and therefore enabling them to access further support if needed. Participant 7 echoed this idea, stating that to cry with a bereaved family is okay, as long as the nurse remains the one providing support.

All of the participants spoke about their team individually, and none were critical of the current team they worked in. Two participants were fairly sweeping with their comments, making the assumption that most community nursing teams were supportive as a unit. However two participants indicated that this wasn't the case,

either having worked in a less supportive environment or seeing nurses in these teams. Participant 5 was less specific, suggesting that nurses can be very unsupportive and uncaring towards each other, creating a culture of blame and mistrust. She goes further to suggest that rectifying this does in part fall down to the team leader:

> *One thing I will always do is support my team and if I hear that they're saying something to me…then I'll always endeavour to make them feel a bit more comfortable cos as a manager, what you're doing is facilitating them…to do their job.* P5

Overall, there was a consensus among all the participants that the team is a crucial part of the support network:

> *Cos if you've got a good team, you've got great morale, you've got great relationships, great communication…it all works doesn't it, for the patient's benefit.* P3

4.7.2 Clinical Supervision

Clinical supervision was described by most participants as the support available externally to the team, a person with whom they met every couple of months to discuss their work in the community. Although it was not described as being solely for the purpose of support, all the participants who currently had supervisors valued it for this reason:

> *It's just a way of…I don't know, not making sure that you, well yes, making sure that you stay on the right track I suppose.* P10

Participant 1 and 7 however were more cynical about clinical supervision, suggesting that it wasn't accessed well by many nurses due to time constraints. Furthermore participant 7 stated that there have not been enough people suitable to be clinical supervisors, therefore many community nurses have gone without. However, although cynical about the organisation of clinical support, neither commented on whether they believed it was a helpful support mechanism.

It was suggested by participant 1 that accessing support was deemed by some to indicate failure, whether clinical supervision or support beyond that:

> *I still think in nursing, to access counselling, or clinical supervision, I do hear and see it is deemed as a failure. There is this perception amongst nurses that if you access anything like that…you really are deemed as a failure.* P1

Many of the participants did not know of any support that they could access beyond their team, their district nurse or clinical supervisors, although some did suggest that Occupational Health would be the next point of call, in the case of something more serious.

4.7.3 Coping

Many of the participants mentioned alternative options for support, for example family, friends or religious beliefs. These were seen as ways to cope with the hard elements of palliative care. Coping was a theme that recurred throughout the descriptions; participant 1 expressed it clearly:

> *I think people have this perception that …you get used to it. No, you never get used to it…I don't know where people get this perception…You learn how to, as a nurse, how to cope with it.* P1

Alongside the ways of de-stressing, for example through the apparent inappropriate humour of nurses as well as times with friends and family, many also described being aware of how emotionally involved they could become, recognising that once they start to take on the patient's burden, it is very easy to become drained. However it was stated that there were always situations that it was difficult to remain emotionally detached from, for example with those patients to whom they could relate easily. In these situations therefore, it was important to identify the emotional involvement, process it and then allow the opportunity of closure. The importance of not taking things personally was also mentioned by participants in preventing burn out.

It is important to mention that participants did also speak of finding palliative care extremely rewarding, particularly in assisting people to stay at home. This is crucial, as knowing that they had made a difference in people's lives was mentioned by six participants as helping them to get through the more difficult situations and building their confidence:

> *I felt privileged that I'd been able to share in that important part of their life.* P3

Despite the time taken to talk about these various ways of coping, and the potential to burn out and become too emotionally involved, none of the participants seemed to indicate that they were in that position. All the comments on this theme were made in an impersonal way, seemingly about others rather than themselves.

It would seem that considering all the different elements of support that the various participants spoke of, an apt term for it would be a support network:

I think you need to have those networks at work so we can all bounce off each other and give each other support. P5

This section particularly identifies how important support is to community nurses carrying out palliative care, where it can come from and how it can enable them to carry out their role effectively. Although most the participants appeared satisfied with the support that they can access, a couple identified problems in how much support is available and the attitudes about those who do access it.

4.8   **Chapter Conclusion**

In summary, the participants spoke on many areas that they felt impacted upon their own confidence as well as touching on themes that they believed impacted on their abilities to care for dying patients, both positively and negatively. These categories and themes will now be considered in relation to the relevant literature in the discussion chapter.

Chapter Five

Discussion

5.1   Chapter Introduction

The question of how confident are community nurses in providing care for patients who are dying arose from my observations of community nurses who seemed to have little confidence in their ability to provide this care. A literature review identified that there was little information specifically on this topic; although confidence was identified as an issue for nurses caring for patients who are dying in the community (Simpson, 2003; Graham et al, 2005; Rose and Glass, 2006). For this reason, this study was carried out, resulting in the findings reported in the previous chapter. The themes identified relating to the confidence of participants were: providing palliative care; personality; experience; training; organisational support networks and interpersonal relationships. These are discussed further within this chapter. However, it is important to recognise that the themes are all woven together, each impacting the others, forming a complex picture of the factors underlying nurses' confidence in providing palliative care.

5.2   Confidence in Providing Palliative Care

Eight out of the ten participants initially stated that they were confident in providing palliative care. However, these participants then went on to discuss areas in which they were not confident, for example, in communication, working with a patient's relatives or dealing with unknown situations. In fact, discussion of these areas dominated the interviews. This immediately introduces an idea that recurs throughout the accounts of the participants; that there is perhaps a difference between the confident, professional nurse that is portrayed when talking generally, and the less confident nurse that is revealed later in the interviews when discussing specific experiences of palliative care. Cornwell (1984, in Atkinson et al, 2003) identified this same occurrence in her study, theorising that participants in interviews may present two different personas: a 'public' persona that is socially

acceptable, perhaps even expected and a 'private' persona that is found deeper within the narratives of the participant. Importantly, neither persona is seen to be more accurate or honest than the other, but rather they present different features of a phenomenon. This touches on the idea of emotional labour (Hochschild, 1983), that a certain professional image should be presented despite any contrasting feelings underneath. In this study, it may be that the expected image of a nurse is of confidence and professionalism; that for a nurse to fall apart would be socially, and professionally, unacceptable to patients, colleagues or even themselves. This idea could be helpful when considering the responses of the participants.

Further insight could be found within the descriptions of the areas in which participants were under-confident. As with the literature review, this study identified that the issues that cause community nurses stress in the area of palliative care are many and varied and that confidence in these areas is often low (Wilkes and Beale, 2001; Rose and Glass, 2006; Seale, 1992). The participants often expressed how they had resolved these problems in the past, or how they would ideally like to do so. When considering the responses of the more experienced participants with those less experienced in palliative care, it was possible to identify three different positions. The more experienced participants had no problem in identifying the areas in which they lacked confidence. Indeed, a number of participants even stated that the more experience they gained and the older they became, the more they felt able to recognise that 'they don't know it all'. This recognition of their weaknesses seemed to give them more capacity to seek out the appropriate resources and support without viewing themselves as failing. This was echoed by participants who stated that the ability to say "I don't know" was central to being able to do the job well. Secondly, a participant with less experience appeared to be able to resolve difficulties in a similar way, acknowledging her inexperience and seeking assistance, often from the more

experienced nurses on their team. This participant also suggested that the phrase "I don't know" was an important one for her to use, particularly with her inexperience in mind. A third response was also from inexperienced participants, but they instead appeared reluctant to admit a lack of knowledge or skills, although this will be discussed later within the section.

Since no literature was found in the original review considering the self-awareness and confidence of community nurses, a second brief search was carried out. This identified some literature relating to the experiences of nurses in the transition from being a student to becoming a staff nurse (Ewens et al, 2001; Maben and MacLeod, 1996; Watkinson et al, 2009). These studies found that some nurses were very aware of their limitations and weaknesses and recognised that they could not meet the expectations of others all the time (Maben and MacLeod, 1996). This self-awareness (defined as 'the conscious knowledge of ones own character, feelings, motives and desires' (OUP, 2010)) was suggested to indicate a high level of confidence in the nurses. With a similar theme coming through in this current study, the same could perhaps be said for these participants; that in recognising a lack of confidence in specific areas, they are actually demonstrating a higher level of confidence in their overall ability to nurse.

A third approach could be seen in the way that two of the less experienced participants presented themselves; they gave the impression that they were in control and no particular problems were arising in their provision of palliative care. This may indeed have been the case. Alternatively, it may be that in showing less willingness to recognise and talk about their own weaknesses, they in fact demonstrate less overall confidence, the reverse of the idea discussed above. Another possibility is that nurses' awareness of their limitations is something that comes with experience. An assumption of competence may thus be a coping mechanism utilised when thrown into unknown and difficult situations, which

commonly occurs for newly qualified nurses. This idea will be followed through in the discussion on confidence and experience.

Personality was a theme touched on by most participants as being a significant factor in both confidence and its growth. Whilst comments often related to the impact of personality on providing palliative care, for example being able to talk with ease about death and therefore being able to communicate more effectively with patients and families, it was also implied that certain personal characteristics are necessary to provide care throughout a career of nursing. Participants mentioned for example being able to not take things personally and therefore protect oneself against burning out, or the importance of reflecting on experiences and practice and learning from this reflection. This theme also arose within the second literature review, in studies exploring the idea of emotional intelligence. Whilst some of this literature considers the importance of self-awareness in nurse leadership (Akerjordet and Severinsson, 2008; Horton-Deutsch and Sherwood, 2008), elsewhere is considered its importance when approaching patient care (Gooch, 2006). Importantly, it is recognised that for nurses to be able to confidently deal with highly charged emotional situations, they need to be able to deal with their own emotions effectively (Freshwater and Stickley, 2004). This brings together some of the ideas in this section, of self-awareness and reflection being important for confidence in carrying out a highly emotive role.

5.3   **Confidence and Experience**

Two aspects of experience appeared important for participants –amount and quality. All the participants agreed that the more experience they had in palliative care, the more confidence they gained. It could be said that this is obvious, yet it was not found written in the literature searched. In addition to this, one participant stated that she believed that she was not sent to palliative patients because of her

inexperience. She therefore was not able to develop her confidence because she had little exposure to it: a vicious circle. This was an interesting perspective, particularly since it was the experience of only one participant. It may be that this reveals a difference between the 'public' account of her team being supportive for inexperienced staff and the 'private' account (Cornwell, 1984, in Atkinson et al, 2003) suggesting this to not always be the case. This idea of team support being significant in defining the confidence of the participants will be discussed later in the chapter.

Considering the emphasis that was placed on experience increasing confidence, it was interesting to hear participants say they were 'dropped in at the deep end' when joining the community. The accounts suggested that they were just expected to get on with it. Although speaking specifically about the transition from student nurse to qualified nurse, the analogy of learning to drive that one participant put forward could also describe learning to provide palliative care in the community; the idea that the most will be learnt when providing the care in practice. This may be why the participants felt that they were just expected to get on with it. Having spoken of the difficulty of this however, it was clear that all the participants felt they had survived being thrown into it; they were, after all, still nursing. The importance of support at this stage was mentioned by seven of the participants however, and mentoring and visiting patients alongside more experienced staff appeared to be an established method of helping nurses adjust to palliative care in the community.

The other side of experience that was mentioned was specific occurrences of providing palliative care that had either a positive or a negative impact on the participants. These experiences were suggested to be hugely influential on confidence, with one participant stating a single negative experience had continued to cause her to doubt her ability in providing palliative care. However, this account

contrasts with those of other participants, who also reported negative experiences but managed to retain their confidence. Although this does not mean it should be discounted, it does raise further questions over the support available, as well as how much personality and personal ability to cope with such situations also impacts the confidence of those providing palliative care.

5.4   Training and Confidence

Participants considered that the training they had received was not adequate considering the large amount of palliative care that they were expected to undertake in nursing in general, but more specifically in the community. Of those who could recall how palliative care had been covered in their pre-registration training, all indicated that they did not feel it was sufficient: they felt they had qualified with knowledge deficits. This is an issue in itself, particularly when considering the increased emphasis on palliative care (DoH, 2008). Further than this, however, the lack of knowledge combined with the negative experiences of caring for dying patients that they had experienced as students, caused some participants to lack confidence in providing palliative care. The experiences of these participants are in contrast to the aims laid out in the End of Life Care Strategy (DoH, 2008) on pre-registration training. However it is important to recognise that all the participants trained prior to the release of this document, and the majority trained before the increased emphasis on palliative care.

On joining the community team, all of the participants received some further training, although this varied in content and when it was attended. The training available within the locality was considered to be very good, providing a sound introduction to palliative care in the community. However, with some participants attending the training as much as two years after entering the community, participants appeared to have been expected to undertake palliative care for some

time without any formal training. When considering that the participants identified many areas in which they lacked confidence, and that the literature identified a lack of knowledge to be a cause of stress for community nurses (Dunne et al, 2005; Rose and Glass, 2006; Simpson, 2003), it could be understood why participants stated that they would appreciate further training.

One participant in a leadership position did suggest that although training is seen as important in preparing nurses to provide palliative care, it is perhaps given too much prominence, that it actually only plays a part in the growth of confidence. Although this idea is represented in the literature (Hopkinson et al, 2005), it does come in contrast to the comments displayed above. It may be, however, that this participant's view developed with experience and leadership responsibility, leading her to believe that more is required than training. When considering the view of Hopkinson et al (2005), that a support framework containing more than just training is necessary, it brings the thoughts of this one participant together with the ideas on support below.

5.5   **Support and Confidence**

The theme of support featured highly in the participant's accounts, suggesting that it has a significant impact on how confident they feel in providing palliative care. The community nursing team appeared to be the primary source of support. Without exception, the participants stated that they were in a supportive team; however, some participants thought that this was not the case for all community nursing teams. This study, in aiming to discover the experiences of community nurses, cannot judge whether of not it is true that some community teams are more or less supportive. However it is interesting in itself that none of the participants recognised this occurring within their own teams, but instead attributed it to other teams. It has been suggested that nurses have been observed

presenting others as inadequate, whilst portraying themselves as the rational, sensible and competent professionals (Li, 2005). In the same way, it could be that the participants in this study were reluctant to criticise their own team or even acknowledge that they work in an unsupportive environment.   Instead, they distance themselves by attributing it to other teams.

In addition to this, the leadership of the community nursing team was highlighted as crucial to how supported the participants felt. Some positive characteristics of a strong leader were identified, as well as recognising that the leader sets the tone of the team.   Although not identifying it as occurring within her own team, one participant did speak of the 'blame culture' that can exist within nursing, with nurses not always supporting each other. Alongside this, another participant stated that accessing support was regarded by some as failure. Although these were the accounts of only one participant in each case, these remain interesting thoughts following on from the discussion on supportive team. Despite not being attributed to any team or nurse specifically, it could be, again, that the participants were reluctant to place direct criticism, instead distancing themselves from a phenomenon they nevertheless felt to be important.

The ideas above could be attributed the more organisational structure that underpins support. However, it appeared that the individual relationships between colleagues and the wider community team were also significant. Knowledge of the people available to give support and advice on practical issues, for example the palliative care link nurses, GPs or MacMillan Nurses, appeared to build confidence in the actual provision of care. Beyond this, the knowledge of people available to give support personally appeared to boost the confidence of the participants in their ability to provide care. These interpersonal relationships therefore appeared to be a central factor in whether the participants felt able to resolve situations that they were not confident in.

However it does appear that there could be some tension between the 'public' idea that the participants know that support is available and therefore feel more confident in providing care; and the 'private' idea (Cornwell, 1984 in Atkinson et al, 2003) that those who need to access this support are sometimes regarded as failing. This may be a feature of less experienced nurses, as the accounts of participants also suggested that with more experience, they gain more capacity to rise above this barrier. It may be that the participants are portraying the appropriate professional image in these descriptions of their confidence. However it certainly adds to the evolving picture of the complex nature of confidence.

5.6   <u>Limitations</u>

As with any study, there were a number of factors that could be viewed as limitations as well as those that could be seen as strengths. These are included to add to the transparency of the research process.

One commonly cited limitation of qualitative research is that the sample size was too small to produce data that can be applied to a wider population. Since the nature of this study however was to discover the experiences of community nurses and gain some understanding of their perspectives, the small sample size is not seen as a limitation. Instead, the interviews yielded large amounts of rich data, indeed too much for this one dissertation. One limitation regarding the sample however was the range of participants. The study was open to hear the experiences of nurses working in the community nursing teams as well as from Community Matrons and MacMillan nurses. However, only nurses within the community nursing teams responded. This may be due to the recruitment methods used, or in part due to the busy schedules of those more specialist nurses. Alongside this, the sample was in effect self-selected; only those who wished to

take part responded, although the response rate of a third was positive. It may be that participants took part because palliative care was an area of interest to them, in which case the interviews do not represent community nurses as a general population. Again however, since the aim was not to produce a theory to be generalised, this need not be a limitation.

The experience of the researcher could also be a limitation of this study. As a student nurse, this was a first time research project, and therefore the researcher had no experience of interviewing study participants. There was therefore an element of nervousness for the first few interviews, potentially impacting upon the ease and flow of the interview. In addition, due to the researcher's age and status as a student, the participants may have been reluctant to share their experiences fully. One participant did comment informally that she felt she could not say anything 'too awful' in case it dissuaded the researcher from continuing in her training. Alternatively however, it is also possible that because the researcher had no position within the local trust, the community nurses felt able to share their perspectives openly as the results of the study would not impact them directly.

5.7   **Chapter Conclusion**

A large number of ideas and themes arose from the descriptions of the participants, presenting a complex picture of confidence and how it is understood and displayed. Confidence doesn't appear to be as it seems; nurses appear to be expected to be confident and this is the image they often portray. However going deeper than this, their confidence levels are impacted by various factors, from their experiences, to the team they work in or their personality, as well as what support is available. This in itself is complex, as support may be available, but nurses may not feel able to access it. Training has in the past been suggested to be important, although the account of one participant indicates that it cannot increase confidence on its own.

Bringing these factors together, it appears that a network of all these different things is needed to really impact upon the confidence of those nurses providing palliative care in the community.

Chapter Six

Conclusion

6.1   <u>Summary</u>

This study set out to investigate how confident community nurses are in providing end of life care in the community. Utilising a literature review to identify what research had already been carried out in the area, it was found that little was known about the confidence of this population. However, previous studies had looked at the experiences of community nurses in providing palliative care, identifying that many areas cause stress within the role, as well as suggesting that the low confidence of community nurses might add to these stressors. Alongside this, some literature was identified which look at the part that training and support have to play in the confidence of the nurses.

Ten semi-structured interviews were carried out with community nurses involved in palliative care to discover their experiences and feelings on their confidence in providing this care. Within these interviews, many ideas and themes emerged, which were identified in the data through the process of analysis. These ideas were categorised, resulting in the main theme categories of confidence, providing palliative care, experience, training and support. The discussion then considered these themes in relation to the literature review.

It quickly became apparent that confidence was not a simple idea and that the confidence of the community nurses seemed to be in layers. Professionally, they presented themselves as confident and competent, able to perform their role and provide palliative care for patients in an appropriate way. However, when revealing more about different aspects of the role, it appeared that they were not as confident as they initially indicated. Rather than this being a discrepancy in their accounts of their confidence, it may be indicate that a need for nurses to present a professional image to those receiving care to gain their confidence and to enable the participants to engage with the patient at an extremely emotive time. However

whilst presenting this image, it may be that they have more uncertainties, more questions and less confidence than the image suggests.

The amount of experience of participants was highlighted to be fundamental in the growth of confidence. Without it, it was difficult to become more confident and at some point the participants suggested that nurses had to be 'dropped in the deep end'. However, the support available at this point was important to the development of confidence.

The importance of a support network around the participants also became clear. The participants suggested that what was available was adequate, but some recollections and experiences appeared to suggest that this was not always the case. Despite this, however, support remained an important concept to the participants. Although the organisational support available, from the community nursing team and clinical supervision, was mentioned frequently, more emphasis was placed on interpersonal relationships with colleagues. Participants indicated that adequate support coming from both of these areas enabled them to provide palliative care as well as to feel confident in their ability to provide it.

Training was mentioned by participants and suggested to play a part in the growth of confidence. However, it was not given the same emphasis that it appears to have received in government documents on palliative care. Bringing this together with the findings on support suggests that a network of these different factors could provide the support needed for community nurses to feel confident in providing palliative care. Although support is important for all nurses, it appears to be especially significant for nurses working with palliative patients, as there is an increased pressure and sense of responsibility when working with people in their last days of life. Enabling these nurses to shoulder this responsibility whilst coping with the pressure appears to be of crucial importance from these findings.

6.2   Implications for Nursing Practice

Palliative care is extremely important in all areas of nursing, regardless of the speciality. Regardless of the professional image portrayed, it remains important to ensure that the nurse behind this image is confident or growing in confidence. Training appears to play a part in this and due to the significant emphasis it is given within recent government documents (DoH, 2008; RCN, 2002) any training needs should hopefully be met. However what appeared to be of greater importance for the participants in this study was the support available to them, both organisationally as well as through their relationships with colleagues. Although the participants suggested that their support needs were often met informally through their community nursing team, there appears to be scope to ensure that this occurs within all teams. Further than this, it may be that there is room to open up conversations on the idea of emotional intelligence and self-awareness within nurses working at ground level, as it may be that this could help nurses to build personal coping mechanisms.

This study seemed to create more questions than it answered, as each different issue introduced by the participants holds possibility for further research. Of particular significance, however, is the idea of the professional image of the nurse versus their private experiences and feelings. Further research could be useful in bringing more understanding of this phenomenon. Adding to this, research looking at the role of personality in how nurses provide palliative care could uncover some interesting findings. Beyond this, further studies considering the support networks for community nurses may be beneficial in understanding how support enables nurses to provide palliative care.

6.3   **Personal Reflection**

The whole process of writing a dissertation, from the beginning stages of developing a proposal, through to it finally being bound, has been a steep learning curve. Words, processes, theories and ideas all previously unknown have had to be learnt about and understood to be able to finish this study. To be honest, it has come as a bit of a surprise to me that it has been an interesting and stimulating process throughout, leaving me with a taster of how research is carried out. In addition to this, I have been able to take away more understanding of the task of providing palliative care, as well as how important confidence is for nurses in this role.

References

Akerjordet, K. & Severinsson, E., 2008. Emotionally Intelligent Nurse Leadership: a Literature Review Study. *Journal of Nursing Management.* 16 pp. 565-577

Aitken, A., 2006. District Nurses' Triggers for Referral of Patients to the MacMillan Nurse. *British Journal of Community Nursing.* 11 **(3)** pp. 100-107

Atkinson, P., Coffey, A. & Delamont, S., 2003. *Key Themes in Qualitative Research: Continuities and Change.* California: AltaMira Press

Austin, L., Luker, K., Caress, A. & Hallett, C., 2000. Palliative Care: Community Nurse's Perceptions of Quality. *Quality in Health Care.* 9 pp. 151-158

Benton & Cormack, 2000. *Gaining Access to the Research Site.* In Cormack, D. Ed. *The Research Process in Nursing*. 4th Ed. Oxford: Blackwell Science. Ch 11

Bishop, V., 2007. *Clinical Supervision: What Is It? Why Do We Need It?* In Bishop, V., ed. *Clinical Supervision in Practice.* 2nd Ed. Basingstoke: Palgrave MacMillan

Bishop, V., 2007. *Clinical Supervision: Functions and Goals.* In Bishop, V., ed. *Clinical Supervision in Practice.* 2nd Ed. Basingstoke: Palgrave MacMillan

Bryman, A., 2004. *Social Research Methods*. 2nd Ed. Oxford: Oxford University Press

Butterworth, T., Faugier, J. & Burnard, P., 1998. *Clinical Supervision and Mentorship in Nursing.* 2nd Ed. Cheltenham: Stanley Thornes

Clissett, P., 2008. Evaluating Qualitative Research. *Journal of Orthopaedic Nursing*. 12 pp. 99-105

Clough, A., 2002. Community Care Policy and End of Life Care: One Patient's Story. *British Journal of Community Nursing.* 7 **(3)** pp. 153-157

Dodd, T., 2008. Quantitative and Qualitative Research Data and their Relevance to Policy and Practice. *Nurse Researcher.* 15 **(4)** pp. 7-14

DoH, 2000. The NHS Cancer Plan: a Plan for Investment, a Plan for Reform [online]

Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4009609

Accessed: 28th January 2010

DoH, 2005. Research Governance Framework for Health and Social Care: Second Edition [online]

Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

Accessed: 16th January 2010

DoH, 2008. End of Life Care Strategy [online]

Available at:

www.dh.gov.uk/en/Healthcare/IntegratedCare/Endoflifecare/index.htm

Accessed: 6th Feb 2009

DoH, 2008. Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own [online]

Available at:

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345

Accessed: 2nd February 2010

Dowling, M., 2007. From Husserl to Van Manen. A Review of Different Phenomenological Approaches. *International Journal of Nursing Studies.* 44 pp. 131-142

Dunne, K., Sullivan, K. & Kerohan, G., 2005. Palliative Care for Patients with Cancer: District Nurse' Experiences. *Journal of Advanced Nursing.* 50 **(4)** pp 372-380

Evans, N. & Walsh, H., 2002. The Organisation of Death and Dying in Today's Society. *Nursing Standard.* 16 **(25)** pp. 33-38

Ewens, A., Howkins, E. & McClure, L., 2001. Fit for Purpose: Does Specialist Community Nurse Education Prepare Nurses for Practice? *Nurse Education Today.* 21 pp. 127-135

Fay, B., 1996. *Contemporary Philosophy of Social Science.* Oxford: Blackwell Publishing

Field, D., 1998. Special Not Different: General Practitioners' Accounts of Their Care for Dying People. *Social Science of Medicine.* 46 **(9)** pp. 1111-1120

Freshwater, D. & Stickley, T., 2004. The Heart of the Art: Emotional Intelligence in Nurse Education. *Nursing Inquiry.* 11 **(2)** pp. 91-98

Gooch, S., 2006. Emotionally Smart. *Nursing Standard.* 20 **(51)** pp. 20-22

Goodman, C., Knight, D., Machen, I. & Hunt, B., 1998. Emphasising terminal care as district nursing work: A helpful strategy in a purchasing environment? *Journal of Advanced Nursing.* 28 **(3)** pp. 491-8

Graham, C., Robson, C. & Whitford, S., 2005. Collusion in palliative care: A reflective account. *Journal of Community Nursing.* 19 **(6)** pp 4-6

Grande, G., Todd, C., Barclay, S. & Doyle, J., 1996. What Terminally Ill Patients Value in the Support Provided by GP's, District Nurses and MacMillan Nurses. *International Journal for Palliative Nursing*. 2 **(3)** pp. 138-143

Griffin, S. & Sawkins, N., 2009. Managing End of Life Care Using the Gold Standards Framework. *Primary Health Care.* 19 **(9)** pp. 22-24

Griffiths, J., Ewing, G., Rogers, M., Barclay, S., Martin, A., McCabe, J. & Todd, C., 2007. Supporting Cancer Patients with Palliative Care Needs: District Nurse' Role Perceptions. *Cancer Nursing.* 30 **(2)** pp 156-162

Hancock, B., 2000. *Qualitative Research.* In Wilson, A., Williams, M. & Hancock, B., Eds. *Research Approaches in Primary Care.* Oxon: Radcliffe

Hochschild, A., 1983. *The Managed Heart.* Los Angeles: University of California Press

Holloway, I., & Todres, L., 2006. *Grounded Theory.* In Gerrish, K. & Lacey, A., Eds. *The Research Process in Nursing.* Oxford: Blackwell Publishing. Ch. 13

Hopkinson, J., Hallett, C. & Luker, K., 2005. Everyday Death: How Do Nurses Cope with Caring for Dying People in Hospital? *International Journal of Nursing Studies.* 42 pp. 125-133

Horton-Deutsch, S. & Sherwood, G., 2008. Reflection: an Educational Strategy to Develop Emotionally Competent Nurse Leaders. *Journal of Nursing Management.* 16 pp. 946-954

James, N., 1992. Care = Organisation + Physical Labour + Emotional Labour. *Sociology of Health and Illness.* 14 **(4)** pp 488-509

Koch, T., 1995. Interpretive Approaches in Nursing Research: the Influence of Husserl and Heidegger. *Journal of Advanced Nursing.* 21 pp. 827-836

Lawton, S & Carroll, D, 2005. Communication Skills and District Nurses: Examples in Palliative Care. *British Journal of Community Nursing.* 10 **(3)** pp. 134-136

Li, S., 2005. Doing Criticism in 'Symbiotic Niceness': a Study of Palliative Care Nurses' Talk*. Social Science and Medicine*. 60 **(9)** pp. 1949-1959.

Luker, K., Austin L., Caress, A. & Hallett, C., 2000. The Importance of `Knowing the Patient': Community Nurses' Constructions of Quality in Providing Palliative Care. *Journal of Advanced Nursing.* 31 **(4)** pp. 775-782

Maben, J. & MacLeod Clark, J., 1998. Project 2000 Diplomate's Perceptions of their Experience of Student to Staff Nurse. *Journal of Clinical Nursing.* 7 pp. 145-153

May, T., 2001. *Social Research: Issues, Methods and Process.* 3rd Ed. Buckingham: Open University Press.

McCann, T. & Clark, E., 2003. Grounded Theory in Nursing Research: Part 1 – Methodology. *Nurse Researcher.* 11 **(2)** pp. 7-18

McNamara, B., Wadell, C. & Colvin, M., 1995. Threats to the Good Death: the Cultural Context of Stress and Coping among Hospice Nurses. *Sociology of Health & Illness.* 17 **(2)** pp. 222-244

Morse, J. & Field, P., 1995. *Qualitative Research Methods for Health Professionals.* 2nd Ed. Thousand Oaks: Sage Publications

NHS Nottingham City, 2009. *End of Life Competency Framework Pilot.* [online] Available at:
http://www.nhsalliance2009.co.uk/Nottingham%20City%20Primary%20Care%20End%20of%20life%20care%20competency%20framework%20pilot.pdf
Accessed: 2nd February 2010

NHS Nottingham City, 2010. End of Life Care Implementation Team [online] Available at: http://www.nottinghamcity.nhs.uk/-your-services-/-citihealth-your-community-services/370-end-of-life-care-implementation-team.html
Accessed: 2nd February 2010

Nottingham City Joint Strategic Needs Assessment, 2009. *End of Life* [online]

Available at:

http://www.nomadplus.org.uk/secure/Intelligence/Health%20and%20social%20car
e/Joint%20Strategic%20Needs%20Assessment/End%20of%20Life%20April%2009.
pdf

Accessed: 2nd February 2010

Polit, D. & Beck, C., 2010. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 7th ed. Philadelphia: Lippincott Williams and Wilkins

Pontin, D., 2000. *Interview.* In Cormack, D., Ed. *The Research Process in Nursing.* 4th Ed. Oxford: Blackwell Science. Ch 24

Porter, S. *Qualitative Research.* In Cormack, D., Ed. *The Research Process in Nursing.* 4th Ed. Oxford: Blackwell Science. Ch 12

Oxford University Press, 2010. *Compact English Dictionary: Self-Awareness* [online]

Available at: http://www.askoxford.com/concise_oed/selfawareness?view=uk

Accessed: 15th February 2010

Queens National Institute, 2008. *District Nursing 150* [online]

Available at: http://www.districtnursing150.org.uk/history.htm

Accessed: 6th Feb 2009

Rose, J. & Glass, G., 2006. Nurses and Palliation in the Community: the Current Discourse. *International Journal of Palliative Nursing.* 12 **(12)** pp. 588-594

Royal College of Nursing, 2002. Competencies in Nursing. A Framework for Nurses Working in Specialist Palliative Care [online]

Available at: www.rcn.org.uk/development/publications

Accessed: 4th Feb 2009

Sawicki, M., 2005. *Edmund Husserl (1859-1938)* [online]

Available at: http://www.iep.utm.edu/husserl/

Accessed: 10th January 2010

Seale, C., 1992. Community nurses and the care of the dying. *Social Science and Medicine.* 34 **(4)** pp. 375–382

Silverman, D., 2005. *Doing Qualitative Research.* 2nd Ed. London: Sage Publications

Simmons, S., 1995. From Paradigm to Method in Interpretive Action Research. *Journal of Advanced Nursing.* 21 pp. 837-844

Simpson, M., 2003. Principles and Practice of Palliative Care. *Nursing Management.* 9 **(9)** pp.9-12

Speziale, H. & Carpenter, D., 2007. *Qualitative Research in Nursing: Advancing the Humanistic Imperative.* Philadelphia: Lippincott Williams and Wilkins

Thomas, K., 2003. *Caring for the Dying at Home. Companions on the Journey.* Oxford: Radcliffe

Todres, L. & Holloway, I., 2006. *Phenomenological Research.* In Gerrish, K. & Lacey, A., Eds. *The Research Process in Nursing.* Oxford: Blackwell Publishing. Ch. 15

Topping, A., 2006. *The Quantitative- Qualitative Continuum.* In Gerrish, K. & Lacey, A., Eds. *The Research Process in Nursing.* Oxford: Blackwell Publishing. Ch. 11

Trigg, R., 1985. *Understanding Social Science.* Oxford: Basil Blackwell

Watkinson, C., Doley, B. & Roberts, S., 2009. Developing a Pre Registration Community Learning Programme. *Primary Health Care.* 19 **(5)** pp. 36-38

Wilkes, L. & Beale, B., 2001. Palliative care at home: Stress for nurses in urban and rural New South Wales. *International Journal of Nursing Practice.* 7 **(5)** pp. 306-13

Wilkinson, S. & Mula, C., 2003. *Communication in Care of the Dying.* In Ellershaw, J. & Wilkinson, S., ed. *Care of the Dying. A Pathway to Excellence.* Oxford: Oxford University Press

World Health Organisation, 2010. WHO Definition of Palliative Care. [online]
Available at: http://www.who.int/cancer/palliative/definition/en/
Accessed: 24th January 2010

Wright, K., 2002. Caring for the Terminally Ill: the District Nurse's Perspective. *British Journal of Nursing.* 11 **(18)** pp. 1180-1185

Appendix One

Appendix Two

Appendix Three

Date

School of Nursing
Katherine Adams
c/o Kristian Pollock
Room 1969, School of Nursing
University of Nottingham
Queens Medical Centre
Nottingham
NG7 2HA
Tel: 0115 8230810
E-mail: ntyakja@nottingham.ac.uk

Address

Dear

How confident are Community Nurses in caring for patients who are dying? A qualitative study of community nurses' experience of providing end of life care in the community.

As a final year nursing student, I am exploring the experiences of Community Nurses in providing care for patients who are dying. I would like to invite you and your Community Nursing team to join this study, through which we hope to see what Community Nurses feel impacts their ability to provide this care.

To take part in the study, participants should be a District or Community Nurse, who has cared for at least one patient requiring palliative care in the last year. In order to gain perspectives from nurses with a wide range of experiences, Community Matrons, Macmillan Nurses and Specialist Nurses are also invited to take part in the study.

It would be greatly appreciated if you, as a Community Nursing team leader, would be able to identify nurses within your team who fulfil these requirements, and distribute the enclosed information sheets to them. The information sheet explains the research in more detail and what it would involve for participants. Please contact us at the above address if there is anything that is not clear or if you would like more information.

The study has been approved by the Nottingham Local Research Ethics Committee and the NHS Nottingham City Research and Development department.

Taking part in the study is entirely voluntary, but it would be very helpful for us to have a definite response (positive or negative) from everyone who has been invited to participate. A reply-paid envelope is provided for this purpose. Alternatively, you are welcome to contact Katherine Adams directly by phone or email:

Yours sincerely,

Katherine Adams   Dr. Kristian Pollock
(Student Nurse Researcher)   (Chief Investigator)

Appendix Four

Katherine Adams
c/o Kristian Pollock
Room 1969, School of Nursing
University of Nottingham
Queens Medical Centre
Nottingham
NG7 2HA
Tel: 0115 8230810
E-mail: ntyakja@nottingham.ac.uk

16th October 2009

How confident are Community Nurses in caring for patients who are dying? A qualitative study of community nurses' experience of providing end of life care in the community.

As a final year nursing student, I am exploring the experiences of Community Nurses in providing care for patients who are dying. I would like to invite you, as a Nurse working in the community, to join this study, through which we hope to see what Community Nurses feel impacts their ability to provide this care.

The information sheet attached explains the research in more detail and what it would involve for you. Please take your time to read it through and make a decision on whether to be involved in the study. Please contact us at the above address if there is anything that is not clear or if you would like more information.

Taking part in the study is entirely voluntary, but it would be very helpful for us to have a definite response (positive or negative) from everyone who has been invited to participate. A reply-paid envelope is provided for this purpose. Alternatively, you are welcome to contact myself directly by phone or email. A reminder letter will be sent out to those who have not responded within a fortnight of receipt of this letter.

If you indicate that you would be interested in taking part, I will contact you directly to arrange a convenient time for an interview.

Yours faithfully,

Katherine Adams
(Student Nurse Researcher)

Appendix Five

How confident are Community Nurses in caring for patients who are dying? A qualitative study of community nurses' experience of providing end of life care in the community.

Participant Information Sheet

You are being invited to take part in an educational research study. Before you decide to take part, you need to understand why the research is being done and what it will involve for you. Please take time to read the following carefully and discuss it with others if you wish. If you would like any further information or if anything is not clear please contact the researchers using the contact details given below.

What is the purpose of the study?

The research is being carried out by Katherine Adams as part of   the course requirements for a Masters of Nursing degree. The purpose of the research is to explore how confident community nurses feel in providing care for dying patients, and how well they feel they are supported in providing this care. Whilst some studies have looked at elements of providing palliative care, relatively few studies have focused on the impact on the nurses themselves of providing this care. Previous studies have suggested that training, or the lack of it, may have an effect of the stress experienced by these nurses. Consequentially, it is important to find out from community nurses themselves how adequate they consider their training in care of the dying to have been, and how it could be improved in the future.

Why have I been invited?

You have been invited to take part in this study because you are a community nurse who has been identified by your team leader as having looked after at least one palliative care patient in the past year. A range of nurses working in the community will be invited to take part the study, including community nurses, district nurses, community matrons, Macmillan nurses and specialist nurses. The nurses interviewed will all work within NHS Nottingham City.

Do I have to take part?

It is up to you to decide whether or not to take part. If you have any questions on getting involved in a research study, please take a look at the INVOLVE website, www.invo.org.uk. If you do decide to take part you will be asked for your written consent at the start of the study. However, you are still free to withdraw at any time and without giving any reasons.

What does the study involve?

The data for this study will be collected through individual interviews lasting for approximately one hour. These interviews will be arranged at a time to suit you, within your working hours, and between the months of September and November 2009. Where possible, they will be held in the health centre in which you are based.

The interview involves an informal discussion, in which you will be asked open questions about your experience of providing care for dying patients in the community, and how well you think your training has prepared you to do this. You will never be under pressure to answer questions or consider any topics you prefer not to discuss. With your permission, the interviews will be audio taped and subsequently transcribed for analysis. Throughout the duration of the research, these tapes and any identifying information about you will be stored securely and will only be accessed by the researchers. The transcripts will be made anonymous and any personal identifying material will be removed. At the end of the study the data will be stored in archives at the University of Nottingham for a period of at least seven years, before being destroyed.

Are there any disadvantages in taking part?

There are no anticipated disadvantages to taking part in this study.

What are the benefits of taking part?

There are no personal benefits to taking part in this study, though we hope the interview will prove to be an interesting experience, in providing an opportunity to reflect on an important aspect of your practice.

Will my taking part in the study be kept confidential?

Any information from which you could be identified that is collected during the course of the study will be kept on a password protected database, or in a locked filing cabinet at the University of Nottingham and is strictly confidential. Any information about you which leaves the research unit will have your name and address removed so that you cannot be identified from it. Only the Researcher and Chief Investigator will have access to any confidential material.

During the transcription process, any personal identifiable material will be removed, and your transcript will be assigned an identification number. This will ensure that you cannot be identified from the transcripts.

What if there is a problem?

If you have a concern about any aspect of your involvement in this study, you should ask to speak to the researchers, Kristian Pollock or Katherine Adams, using the contact details given below. They will do their best to answer your questions and address your concerns. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from NHS Direct on 0845 4647,

What will happen to the results of the research study?

As the study is being carried out for educational purposes, it will be written up in the form of a dissertation. A summary of the findings will be sent to all participants when the project has been completed.

Who is sponsoring the research?

The study is being sponsored by the University of Nottingham.

Who has reviewed the study?

This study has been reviewed and approved by the Nottingham Local Research Ethics Committee.

Contact for further information

Katherine Adams, Student Nurse Researcher
c/o Kristian Pollock
Room 1969, School of Nursing
University of Nottingham
Queens Medical Centre
Nottingham
NG7 2HA
Tel: 0115 8230810
E-mail: ntyakja@nottingham.ac.uk or Kristian.pollock@nottingham.ac.uk

How confident are Community Nurses in caring for patients who are dying? A qualitative study of community nurses' experience of providing end of life care in the community.

Taking part in the study is entirely voluntary, but it would be very helpful for us to have a definite response (positive or negative) from everyone who has been invited to participate. A reply-paid envelope is provided for this purpose. Alternatively, you are welcome to contact Katherine Adams directly by phone or email:

Reply slip:

Please delete as appropriate:

I am happy to be contacted/ I do not want to be contacted regarding the study on community nurses and the care of the dying.

Name_____

Phone number_____

Email Address_____

Work Base _____

Please use the reply paid envelope to return this slip to Katherine Adams, c/o Kristian Pollock, Room 1969, School of Nursing, Queen's Medical Centre, Nottingham, NG7 2HA or phone 0115 8230810 or email ntyakja@nottingham.ac.uk.

Appendix Six

The University of Nottingham

Participant Identification Number:

CONSENT FORM

How confident are Community Nurses in caring for patients who are dying? A qualitative study of community nurses' experience of providing end of life care in the community.

Name of researcher: Katherine Adams
Chief Investigator: Dr. Kristian Pollock

Please initial box

1. I confirm that I have read and understood the information sheet dated 21.6.2009 version 2 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. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis

3. I agree to the interview being tape recorded for the purposes of the research. I understand that I may ask for the tape recording to be stopped at any time.

4. I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the NHS Trust, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

5. I agree to the use of extracts from the interview being included in the Researchers' Masters of Nursing Science dissertation and any subsequent published output from the study. I understand that all personal details will be removed and I will not be identified in any such output.

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

_____   _____   _____
Name of Participant   Date   Signature
_____   _____   _____
Name of Person taking consent   Date   Signature
1 copy for participant; 1 to be kept as part of the study documentation

Appendix Seven

Interview Topic Guide

- How old are you and when did you enter nursing? Where did you train?

- Can you recall one particular experience of caring for someone at the end of their life?

- How would you describe your current level of confidence in caring for a dying patient? Why?

- What do you feel impacts your confidence to be able to provide care for a dying patient?

- Do you think it is possible to increase your confidence?

- How would you describe the training you received in this area pre-registration?

- And the training offered once working in the community?

- What support networks are available to you?

- What are your suggestions for improvement in this area?