

**CERTAIN THE CURRICULUM;
UNCERTAIN THE PRACTICE:
PALLIATIVE CARE IN CONTEXT**

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CERTAIN THE CURRICULUM; UNCERTAIN THE PRACTICE: PALLIATIVE CARE IN CONTEXT

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PROMOTER: DR NYNA AMIN

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DEDICATION

For my mother, Esther

DECLARATION

I declare that this dissertation is my own production, original in conception and execution, and has not been submitted heretofore to any other institution for examination.

Further, all sources are acknowledged, and cited in the bibliography.

Researcher _____

Promoter _____

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Carl. R. Rogers in his influential book *Becoming a Person* (1961) notes that it is of enormous value when we permit ourselves to try and understand another person. I have found it enriching and inspiring to try and understand the lives of those I work with in South Africa. Nurses and ‘home-based care (HBC) workers’, the participants for this study, travel into impoverished homes in isolated rural areas and generously offer their care to patients. Their patients have little access to any other form of care, and I have witnessed nurses and HBC workers taking food and clothing from their own homes to give to those who have nothing. Because understanding their generosity and appreciating their joy for life is rewarding and because this study has allowed me to become a better person, I would like to thank the caregivers who kindly donated their time and energy for this study. I would like to thank the managers of HBC organizations for permitting me to approach the caregivers.

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ABSTRACT

This study opens in a critical paradigm and explores the previously unheard experiences of caregivers who have been trained in and who practice palliative care in a context of rural African, isolated, profoundly impoverished homes. Instead of a healthcare focus, the study used curriculum theory to provide a fresh look at and to better understand palliative care in context. Curriculum theory distinguishes a curriculum as preactive (espoused) or interactive (enacted), and preactive and interactive curricula for palliative care were compared and interrogated as exemplarity of a circumstance when a curriculum is transported into a context other than that where it originated.

The study offers several contributions to health sciences, including a link between curriculum theory and palliative care, and provides deep insights into the experiences of those who practice palliative care with limited guidance and support from senior healthcare professionals.

In the 1970s palliative care developed in a hospital context in the United Kingdom as a response to ideas which included that society is death-denying and that medicine and associated sophisticated technology act to render patients passive spectators in care decisions. An aim is to coordinate and plan care which includes a focus on empowering patients and their families by giving them choices around living with a life-shortening illness and dying as comfortably and peacefully as possible. A common theme is an intention to relieve or prevent suffering, and palliative care services have developed throughout the world. Palliative care is delivered by healthcare professionals acting within a multidisciplinary team who provide care at various sites including hospitals, homes and hospices.

Palliative care has been introduced to post-apartheid South Africa relatively recently, and the preactive palliative care curriculum is largely based on notions of palliative care which developed in a European context while the interactive curriculum is enacted in rural African homes.

Ideas around palliative care may not have a universal or rigid quality, but may represent an agreement among people in a certain context and the unexplored introduction of such ideas into another context may potentially give rise to a hegemonic flow of ideas. Systemic challenges around healthcare in Africa may preclude a patient from having choices in their healthcare. The agency of patients may be undermined by their material living conditions.

The study site was rural KwaZulu-Natal in South Africa, where the incidence and prevalence of Human Immunodeficiency Virus are the highest in the world. Study questions revolved around a curriculum as a source of knowledge for practice and experiences of a context and practice. Data sources were twofold: firstly a palliative care curriculum text was scrutinized and analyzed in terms of who is cared for, place of care, work of caregivers and palliative care; and secondly data from participants (nurses and home-based care workers) were analyzed to produce deep insights into their experiences of practising in context. Data were generated using a visual technique of “photo-elicitation”, where participants were invited to discuss photographs they took to convey their experiences, and analyzed inductively using naturally emerging themes.

Curriculum data indicated that patients should be offered palliative care when there is awareness that they face a life-limiting illness, and a focus was on home care. The espoused curriculum foregrounded physical care and placed less emphasis on aspects such as spiritual, cultural or psychosocial care; the curriculum was delivered at a site distant to caregivers’ practice. In South Africa the legacy of apartheid lingers, and data from caregivers revealed that physical conditions are harsh in that patients are starving, housed in makeshift shelters and face profound social challenges. Spiritual care and cultural care were highly valued, as patients map onto traditional beliefs and cultural practices

Data revealed that caregivers were sometimes unsure, angry, felt powerless and could be placed in physical and emotional danger. Patients and their families valued some aspects of palliative care, such as preparing for death and bereavement support, but found challenges in understanding other aspects such as why caregivers did not appear to make attempts to cure disease.

Juxtaposing study findings with published literature revealed that diametric worldviews of teachers and learners have an impact on curriculum delivery. The home could be a beneficial place for care but could also create challenges.

The study theorizes beyond a palliative care curriculum, and in concluding the study I found that I must move from a critical to a post-structural paradigm. A critical paradigm seeks data around oppression and marginalization so that transformation may be enacted, and data indicated that aspects of the practice of palliative care were both empowering and disempowering for caregivers; they were empowered by being able to practice in an independent, autonomous way, but were also disempowered since the curriculum did not adequately consider context.

The study unearthed no universal truth for a curriculum for palliative care; an African curriculum should take cognizance of an African context. I use the study findings to put forward a thesis around certainty in curriculum, and the study prompts understanding of certain curriculum in contexts that are uncertain.

Key words: Certainty, curriculum, palliative care practice, context, rural homes

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PART ONE

INTRODUCTION TO AND OVERVIEW OF THE STUDY

This is a study about curriculum and palliative care in context. I will explain aspects of curriculum and palliative care at length throughout the study, and by context I mean the place, the space and the geography where the social, psychological, cultural, spiritual and physical aspects of a person living within a society all come together. The study is structured in five parts, and a summary of the parts and associated chapters is represented diagrammatically below.

PART	CHAPTERS			
Part One Introduction and overview of study	Chapter One: Researching curriculum for palliative care in rural homes			
Part Two Background: The landscapes of palliative care, curriculum and rural homes	Chapter Two: A landscape of palliative care	Chapter Three: A landscape of curriculum	Chapter Four: A landscape of rural homes	
Part Three Methodological forays: Paradigms and data production	Chapter Five: A paradigmatic foray	Chapter Six: A methodological foray		
Part Four: Working with data	Chapter Seven: Exploring curriculum as a knowledge source	Chapter Eight: Exploring how caregivers experience a context	Chapter Nine: Exploring caregivers' experiences of a practice of palliative care	Chapter Ten: The curriculum and practice in context
Part Five: Thesis	Chapter Eleven: Curriculum certain; practice uncertain: palliative care in context			

Figure 1: Diagrammatic representation of the structure of the study

Part One provides a global review of the study and comprises Chapter One. Three key aspects of the study are palliative care, curriculum and context (rural homes), and Part One provides a brief introduction to the background to each of these, which is further expanded in Part Two. Part Three focuses on the paradigmatic orientation of the study and on methods used to generate data. Part Four, which forms the largest part, works with data and here data are presented, analyzed and juxtaposed with published literature. Part Five presents the thesis. At the start of each part I will remind the reader of the purpose of that part.

Let me begin with Part One which, comprising the first chapter, highlights important features of the study and provides a brief overview of salient points required for understanding the study in its entirety.

CHAPTER ONE

Researching a curriculum for palliative care in rural homes

1.1 Introduction

Part One, Chapter One provides an introduction to and overview of the study and is required as a foundation for understanding the rest of the study. The specific aims of this chapter are fourfold: firstly, I briefly introduce the reader to qualitative methods and to my decision to focus on curriculum for palliative care. Secondly, I provide a rationale for the study, present the study questions and make explicit the significance of this study. Thirdly, I provide a short overview of curriculum, palliative care and context and this overview is particularly essential for the reader to make sense of the rest of the study. Fourthly, I expand on the structure of the study, which I alluded to in Figure 1.

1.1.1 Overviewing qualitative research and a space between curriculum and palliative care

This study about curriculum and palliative care in rural homes uses qualitative research methods and is situated in a space between educational studies and health sciences (by which I mean medicine and nursing). At the outset I request suspension of judgment about this interdisciplinary study until the entire study is read. The writing may seem verbose, not conforming to traditional health sciences, quantitative approaches and the associated formats of scientific report writing. The reader may wonder why a study in palliative care is carried out in a qualitative way (not usually associated with health sciences) and why a focus is on curriculum. Let me expand on these two issues.

In health science research ways of seeing the world, or paradigms, are generally not spoken about because there is an understanding and acceptance that there is only one paradigm and that paradigm favours rationality, objectivity, logic and evidence (Henning, van Rensburg & Smit, 2004). In a qualitative world there is an acceptance that there are multiple ways of seeing the world which operate simultaneously.

Qualitative researchers strive to acknowledge and embrace uniqueness and individuality and an emphasis is placed on understanding ways in which individuals create, modify and interpret the world in which they find themselves (Neuman, 2000). In contrast to the worldviews of quantitative researchers, qualitative researchers have devised ways of understanding which paradigm a researcher is situated in. Paradigms are not pristine, mutually exclusive, clearly demarcated categories and, for example, social scientists consider it important for a reader to be aware of the way in which the researcher is viewing the world. Part Three of the study will provide a detailed explanation of the worldview of this study, and at this stage it is pertinent to provide a synoptic mapping of five generic paradigms: positivist, interpretivist, critical, feminist and post-structural.

Positivism is strongly associated with science and is based on a view that things in the world can be predicted, and issues such as generalizability,¹ reliability,² and validity³ become important criteria to ensure and understand the rigour of the research method. It is important to declare that scientific research in the way positivists approach it is important, relevant and necessary. This study does not aim to detract from positivist research, which has led to important discoveries that have saved lives and improved quality of life and care. There is a need for positivist research in health sciences, but positivism should be tempered with other paradigms. Literature reveals that with regards to palliative care some researchers appear to operate within a positivist paradigm as, for example, they call for a “common language for palliative care” and “an evidence base”:⁴

¹ In generalization, the researcher aims to move findings from a sample to a larger population (Cohen *et al.*, 2011).

² Reliability is essentially a synonym for dependability, consistence and replicability over time, over instruments and over groups of respondents. It is concerned with precision and accuracy (Cohen *et al.*, 2011, p. 199).

³ In quantitative research validity implies that a particular instrument in fact measures what it purports to measure, or that an account accurately represents those features it is intended to describe, explain or theorize (Winter, 2000).

⁴ The idea of evidence-based practice conveys the idea of a rigorous and critical approach to the development and evaluation of clinical expertise while maintaining a strong commitment to patient-centredness and humanistic values (Sackett *et al.*, 1996). In evidence-based practice a hierarchy of evidence exists where evidence is rated or ranked according to the data collection method (Evans, 2003). Data from a quantitative study involving clinical trials is more highly rated than other forms of data collection (such as qualitative methods).

Definitional issues are limiting generalizability in palliative care: palliative care, perhaps more than any other medical discipline, experiences problems in translating research evidence into practice. Clinical definition itself lies at the root of the problem. A lack of a common terminology frustrates clinicians' efforts to draw conclusions from research literature and to apply that evidence to their local clinical setting and ultimately this (lack of common terminology) limits the development of evidence-based medicine and may be limiting the care that can be offered to people at the end of life (Powell, Downing, Harding, Radbruch & Mwangi-Powell, 2008, p. 885).

Researchers appear to be frustrated that palliative care does not always seem to conform to positivist notions such as definition, common terminology and generalizability. Powell *et al.*, (2008) suggest that quantitative ideas, such as definitions and validated outcome measures, should be prioritized in African palliative care. Quantitative palliative care work can be found in tools such as 'The APCA [African Palliative Care Association] African Palliative Outcome Scale (POS)', which is a tool devised to measure patients' physical symptoms, psychological, emotional and spiritual needs, and provision of information and support at the end of life (Powell *et al.*, 2008).⁵ Harding *et al.* (2010a, p. 1) note that such a tool is required to "*address the omissions of palliative care research in Africa*". I am in no way disputing the value of such quantitative tools and quantitative research; however, this POS tool could be critiqued for focusing on measurement and for focusing solely on the patient and excluding the views, opinions and experiences of others, such as caregivers, trainers, curriculum designers and programme managers. I argue that working exclusively in a quantitative way will not fully address the omissions of palliative care research in Africa.

⁵ The APCA African POS contains 10 items, addressing the physical and psychological symptoms, spiritual, practical and emotional concerns, and psychosocial needs of the patient and family. The answers to all questions are scored using Likert scales from 0 to 5, with numerical and descriptive labels. Questions 1-7 are directed at patients; questions 8-10 are directed at family informal caregivers and include a 'Not applicable' option for use when the patient does not have an informal carer. The African version of the POS is staff-completed, owing to varying levels of patient and family literacy. Respondents indicate their answers either verbally or using a hand scale (0 = closed fist, 5 = all fingers open).

Understanding differing views of the world is important in the interpretivist paradigm, and a critical paradigm considers issues around oppression and emancipation (Hesse-Biber & Leavy, 2011). A feminist paradigm focuses on liberation of women. This could have been a gender study as I am a woman and the participants are women, and I initially worked in a feminist paradigm (in Appendix A, the reader will note that the original title of the study invited a feminist exploration of palliative care). However, reflecting on data, I have chosen not to carry out the study in a feminist paradigm since the data did not strongly support that issues were strongly related to female gender. There is a lot of literature on the gendered nature of caring (e.g. Nel Noddings, 1984). In future I, or others, may adopt a feminist stance and explore palliative care curriculum from a feminist standpoint.

A post-structural paradigm shows how language works in an arbitrary way, and the French philosopher and historian Michel Foucault came to be seen as the most important representative of the post-structuralist movement. He advocated that language and society were shaped by rule-governed systems, and proposed that it was impossible to step outside language or discourse and survey a situation objectively (Foucault, 1972). Jacques Derrida (1976) developed deconstruction as a technique for debunking discourses and uncovering multiple interpretations of texts. He suggests that all text has ambiguity, and because of this the possibility of a final and complete interpretation must at most be tentative and must consider the role of power. Throughout the study I indicate which paradigm I am working in and why. This study begins with a critical stance and in keeping with this paradigm I foregrounded the voices of participants and their interpretation of the world and not my (the researcher's) voice. As I explain in Part Three, participants were given cameras and requested to take photographs which they felt enabled them to describe their daily work. The data collection method did not involve the researcher and participants were given freedom to discuss whatever they felt was important to them, a concept known as democratic participatory validity (Vithal, 2003). Participants had the right to photograph, make meaning of and interpret their world without interference or influence from the researcher. In a critical paradigm I aim to expose how their context makes their work so difficult. Critical research is usually carried out to prompt transformation, but this is not a specific aim in this study. I do not explicitly want to bring about change, rather I want to expose and make visible the challenges faced by palliative care practitioners.

These challenges are faced in context, and a curriculum may not have prepared them for such challenges; in a critical paradigm a curriculum may be regarded as oppressive if challenges faced by palliative care providers in context are not considered. Activation of change may arise after the study but does not arise within this study, and the reasons for not bringing about change will become apparent as the thesis unfolds.

The study lies at the interface between medical/nursing care of people who face a life-limiting illness and curriculum studies. It could not be carried out exclusively within a health science space as health science education may be underpinned by theories associated with curriculum which are not visible or overt. In my view the practice of medicine and nursing should be underpinned by a sound curriculum theoretical foundation which is visible so that it can be scrutinized and understood. Let me expand on what I mean. Doctors and nurses are taught about practice of medicine and nursing and what is taught represents someone's ideas around practice, and as such these ideas may be viewed in curriculum based on work carried out in laboratories or in controlled experiments. The study aims to expose a gap between curriculum and practice, and a gap could raise serious questions of the prescribed curriculum or consider how context is far removed from curriculum. The reader will gather later that this is not a new idea.

In the final stages of my study, in order to deepen understanding and bring about new insights, I found that I must move from a critical towards a post-structural view of the world to show the paradoxes between certainty and uncertainty. Throughout the study it will become clear why I must make this move. The data reveal that there are both certainties and uncertainties in a curriculum. For example a palliative care curriculum was certain that care should be provided for a patient with a life-limiting illness, and practice reveals that the caregiver cannot be sure whether the patient has a life-limiting illness or not. A palliative care curriculum was uncertain about spiritual aspects of care, and caregivers were certain that these aspects of care were important in this context. One part of any curriculum operates in an abstract way and another gets activated in practice, and this study will show that while a gap between a curriculum and a practice may not be able to be overcome, it should not be viewed in a negative way. Any gap should be acknowledged and valued as a site of emerging possibilities, rather than a deficit to be filled or closed.

Although I have conducted this study in a qualitative space, I apply the rigorous criteria expected of such a study process. Rigour in a qualitative study is based on criteria different to rigour in quantitative studies. For example, in quantitative research a criterion for scientific rigour is replicability, and this concept shares much with reliability in that both refer to the extent to which a research operation is consistently repeatable (Searle, 2004). Neither generalizability nor replicability are issues in this study, because the idea is not to generalize a sample to a larger population or replicate the study to get the same findings elsewhere.

In fact, in qualitative work every type of study will yield different types of findings. Therefore the aim of this study is not to come to a truth about palliative care: rather, a powerful contribution of this study considers how palliative care gets shaped by the context of the people who practice it and the patients who are recipients of palliative care.

Another criterion for rigour in quantitative research is validity, which considers whether the instruments used to measure are producing an accurate representation of the phenomenon under measurement. In qualitative work there are many ways in which validity is constituted within a study, and Maxwell (1992) cautions qualitative researchers not to work in pursuit of an agenda of demonstrating predictable outcomes, noting that notions of validity should be replaced with notions such as authenticity. Authenticity considers how authentic the data are and specifically if the data which emerge are commensurate with the context in which the study was conducted.

Mishler (1990) believes that “understanding” is a more suitable term than “validity” in qualitative research. Qualitative validity attaches to accounts and not to data or methods. Lincoln and Guba (1985) suggest that another key criterion for validity in qualitative research is trustworthiness, for example, rigour can be achieved by careful audit trails. Trustworthiness explores if the researcher is someone who can be trusted and if the data are plausible and not manufactured in the mind of the researcher. In qualitative research a way to check validity of research findings is to employ the technique of triangulation which is using two differing methods to review the same research questions and looking for convergence in research findings (Greene, 2007). In this study there is no seeking for triangulation by using two different methods to review the same research question as it is expected that participants will have differing experiences and a triangulation method applies only to the researcher; are the claims made by the researcher triangulated by the evidence from participants’ data?

Particularly in this study, a notion of generalizability does not apply, and the study relies on “generativity” which is a form of generalizability (Vithal, 2003, p. 115).⁶ Generativity relies on the reader to decide whether the findings from this study apply to their own context, and the researcher does not dictate to which context it can be generalized. Qualitative work considers that truth or ways of looking at the world are not universal as each individual may see the world differently, and the study is about understanding how people in their own context experience palliative care practice.

Qualitative work considers how knowledge is produced and as such does not operate on an objective stance and involves interacting, communication and getting into the minds of participants. The focus of this study is on people: the caregivers who practice palliative care and the patients who receive palliative care. In this study, data of the patients are not used directly, and patient voices come indirectly through the voices of caregivers. Patients do have a presence in the study which is invisible yet simultaneously present. People are integral to understanding this study, which does not focus on objective inanimate issues such as medications and scans, and the voices of people are deeply infused throughout data presentation and analysis. This study does not aim to detract from the work of positivist research; it rather aims to put people at the centre of enquiry. This approach is commensurate with the emotional aspect of caring, which influences the way palliative care is practised and received. In this study I invite the reader into the lives of caregivers who work in rural areas.

1.1.2 A rationale for the study

Palliative care is not clinical, abstract and objective work. It is infused with trauma, suffering and pain that are physical, emotional, cultural, psychological, social and sympathetic, and deals with hopelessness and futility. I have experience of palliative medicine in that I studied for a Diploma in Palliative Medicine in Cardiff in 2001 and have a Masters in Palliative Medicine from The University of Cape Town (2003).

⁶ In medicine generativity implies an awareness of people besides self and family that usually develops during middle age. It describes a need to nurture and guide younger people and contribute to the next generation. It is used in the psychology of Erik Erikson. In a critical research setting Vithal (2003, p. 115) uses the term to convey an intention to inspire new forms of practice and new theory building.

I am a Family Medicine Physician⁷ who trained as a doctor in Scotland and who has worked in rural hospitals in KwaZulu-Natal, South Africa for 20 years. I have been involved with developing and implementing an embryonic palliative care service at a rural hospital and wish now to support expansion of palliative care services through teaching and research at the University of KwaZulu-Natal, where I am affiliated to the Department of Family Medicine.

As a rationale for this study I provide three stories in three contexts in which people suffer and are from differing social classes and cultural backgrounds. Common to these stories is my involvement as both a medical doctor and as a family member experiencing suffering and patients who are women and mothers. In a first story I discuss a patient who was cared for in a hospital. I visited this patient when I just started my medical training, and was a witness to her unfolding story.

My patient, the mother

Mary was 45 years old and ill in a hospital in Scotland. She had a cancer of the breast and had major operations to her breasts in an attempt to remove the cancer. A course of radiotherapy directed radioactive material at the tumour. Her skin was burnt, blistered and painful. A course of chemotherapy involved injecting medications into her bloodstream. She lost all her hair and felt nauseous and exhausted most of the time. Many differing people were involved with her care. An oncologist visited daily and supervised her chemotherapy. A pulmonologist (lung specialist) reviewed her lungs and recommended a bronchoscope where a tube is placed in the lungs to look for disease. A nephrologist (kidney specialist) reviewed her blood tests and recommended that she have a blood test daily. A hepatologist (liver specialist) recommended that she have an operation to remove tumour from her liver.

⁷ My position is roughly equivalent to a “hospitalist” in the UAs or an “associate specialist” in the UK. Hospital medicine in the USA is the discipline concerned with the medical care of acutely ill hospitalized patients. Physicians whose primary professional focus is hospital medicine are called hospitalists; this type of medical practice has extended beyond the USA into Canada. The practical effect of the hospitalist is to act as transition coordinator and case manager, due to the tremendous growth in medical knowledge and resultant number of medical specialists. In the UK an “associate specialist” doctor is one who is appointed to a permanent position in the middle ranks. The rank is the highest that a doctor not seeking to be made a consultant may achieve, and is usually conferred upon doctors who have several years of experience of working in hospitals.

Mary mentioned to me that she was confused as the doctors seemed to tell her things which she could not understand and one doctor told her that she could go home while another told her that she must remain in hospital. She seemed to want to discuss her fears, her anger and her sense of futility with someone, as she told me she thought that she faced death. She was also very anxious about her children.

She told me that her husband, Martin, was frightened and angry and felt that the oncology doctor did not include him or his wife in decisions about treatment. Mary's two young children were afraid of the hospital and wished to spend time with their mother at home. "Can Mummy come home?" they asked me repeatedly.

Despite all medical interventions, the cancer continued to spread from her breast throughout the rest of her body. None of the doctors told her that she faced death. The oncologist advised her to remain in hospital and to continue the prescribed treatment. Mary continued to have chemotherapy and continued to have pain and nausea and was very anxious. Her husband appeared to be angry. Her children continued to ask me about their mother returning home until she died.

In the second story I use a poem to describe my feelings while my mother died in a hospice. I was a final-year medical student.

My mother

I sat with my mother as she died.

I sat as a large, brooding, dark and silent elephant in that room.

"Tell Laura that she must give her mother permission to go," the doctor said to the nurse.

I seethed with anger.

I never gave her permission to go.

And no one noticed that the elephant in the room was me.

In the third story, I was a medical doctor working at a rural hospital. A friend who worked as a palliative care nurse for a local home-based care (HBC) organization requested that I accompany her to a patient's home. Doctors are not usually involved with home-based palliative care.

My patient, the grandmother

At the request of a nursing friend I visited the home of an elderly Zulu⁸-speaking lady in a rural area of KwaZulu-Natal,⁹ South Africa. The grandmother cared for five young, orphaned grandchildren. The youngest child had Acquired Immune Deficiency Syndrome (AIDS) and my friend asked me to review a skin condition. The home was a one-roomed hut situated at the end of a long, winding dirt path. There was no electricity and the room was filled with a stagnant, pungent smell of fire and cooking. The grandmother's teeth were broken and discoloured, her dress thin and faded. In the gloom of the hut, a dark, silent child lay immobile on a mattress on the floor.

The nurse and granny spoke in Zulu (I do not speak Zulu). "The granny requests that you step outside, Doctor Laura," said Nkosazana, the nurse. I stood outside in the hot sun, shuffling my shoes idly in the dust and waited until Nkosazana left the hut. "Why did granny want me to step outside?" I asked.

"Because she thinks that the doctor only comes when the child is dying. She does not want the child to die. What can I do to help this child and her grandmother?" What can the nurse do?

These stories dredged up from my past have, to a large extent, inspired this study. Each context, Scotland, Ireland and South Africa, threw up dimensions of suffering and pain when death was imminent, and they have urged me to include the human person not on the periphery but at the centre of the study. In the first story a mother and her husband and children suffered in a hospital in Scotland. The second story captures the anger I experienced as a final-year medical student and as a family member who cared for a mother who was dying in a hospice in Ireland. I was not given any opportunity to become involved with care decisions until it was too late. The third story illustrates a grandmother's suffering. As a doctor I offered a grandmother in a rural home an opportunity to discuss and make decisions around the illness of her grandchild and was politely rebuffed.

Throughout my career I have been inspired by the work of Carl R. Rogers. He opens his influential book *On becoming a person* (1961, p. 1) advocating that we can become better people through our service to others. As I will explain later, palliative care emerged as a way of caring in the United Kingdom (UK) and was brought to South Africa, which represents a palliative care-naïve (or what I term "new") context.

⁸ Zulu is the most commonly spoken language in KwaZulu-Natal.

⁹ KwaZulu-Natal is one of nine provinces in South Africa.

Palliative care is concerned with service of people and aims to alleviate suffering and focuses care on a patient, family and caregiver. People who may face an end to their life through illness can be thrown into a previously unknown world of frightening medical machinery, doctors, nurses and scans. They may have many questions and may become confused and vulnerable.

Patients, their families and caregivers may become better people through care for a patient who faces death, which is named palliative care. I use this study to find out more about a curriculum for palliative care in the context of rural patients' homes. I could have approached the study from several perspectives; I could have looked at how it is to be a doctor who practices palliative care, or how it is to be a family member who experiences palliative care. However, I have existing experience of being a doctor who tries to provide palliative care in hospitals. I have existing experience of how it is to be a family member who faces the death of a relative in a hospice. I do not, however, have knowledge of how it is to be a nurse who must provide palliative care, without support from a doctor, in a rural home.

The choice to look at the question of what is it like to be a nurse who offers palliative care in rural homes may provide us with another piece in a puzzle of home-based palliative care. Participants in this study were nurses who were trained in palliative care using a preactive curriculum and who practice palliative care in rural homes. In the context of the study there are few trained nurses practicing home-based palliative care, and participants also included non-health professionals known as "home-based care (HBC) workers". I made an assumption that these HBC workers were indirectly trained in aspects of palliative care by the participant nurses. This study only considered the curriculum for nurses, and an assumption was made that the curriculum for HBC workers was based on the nurses' palliative care curriculum as no other curriculum was available. Throughout the study I generally refer to the participants as caregivers since the word 'participant' seems to be clinical and detached. I have worked with the caregivers for several years and view them as more than participants who are subjects of a research endeavour.

As I explain in the following chapter, the idea of palliative care developed in a Northern¹⁰ hospital context and has recently been introduced into a context of homes in the South.¹¹ By the South, I mean the African continent, and the rural context of Africa is evoked emotively by caregivers throughout the data. I acknowledge that I present the North and the South as broad generalities and in doing so intersections and overlaps are marginalized. I also acknowledge that I run a risk of essentializing both contexts. I ask the reader to bear with me as the idea is to present a notion of a curriculum within one context and I do not suggest that findings can apply to another context.

A curriculum for nurses who provide palliative care has been developed for implementation in a Northern context, where nurses are generally well supported within a larger healthcare system. The situation is quite different in the South: patients are materially impoverished and a home-based nurse may have little access to formal healthcare facilities such as hospitals or clinics. Hence this situation offers the opportunity to study a curriculum as the palliative care curriculum is of considerable importance in acquiring knowledge in a palliative care-“naïve” context. I am particularly interested in curriculum, and concur with Begoray and Banister (2005, p. 296):

While learning and teaching are fundamental concepts in health contexts, the corresponding development and analysis of curriculum theory in the development of programs is not generally a focus of study. Society at large tends to link interest in curriculum issues to the school setting. Such settings are however not the only setting for educational pursuits. ... Implementing curriculum theory is particularly appropriate for programs where practitioners hope to develop and sustain new understandings and healthy behaviors.

¹⁰ By the North I mean industrialized or developed countries. Such developed countries are generally in the north, for example United States of America, United Kingdom, France and Canada. I use the term to include Australia, New Zealand and other developed countries. These countries generally share similar Westernized worldviews.

¹¹ By the South I mean developing countries and I include countries such as South Africa, Brazil, Venezuela and Mexico.

Begoray and Banister (2005) suggest that curriculum theory is generally neglected in health sciences such as medicine or nursing. I agree that curriculum is important; however, it is difficult to develop a theory for Southern palliative care based on notions about palliative care which arise in the North.

I argue that there is a need to foreground the experiences of those who have experienced a preactive curriculum and practice a palliative care curriculum in African rural homes.

1.1.3 Study questions

The four questions which this study will address are:

- What knowledge informs caregivers' palliative care practice in rural homes?

This question explores curriculum as a source of palliative care knowledge used to prepare caregivers for palliative care practice. Four aspects of curriculum will be explored: who is cared for, caring at home, roles of caregivers and expertise in palliative care.

- How do caregivers experience the context of palliative care?

This question explores what it would be like to be a caregiver providing palliative care. In their experiences what are homes like? What support is available? What are their main challenges and how do they feel?

- What are caregivers' experiences of palliative care practice in patients' rural homes?

This question attempts to fathom the ways caregivers experience a practice of palliative care curriculum within their own context. I acknowledge that their experiences of practising palliative care may be influenced by a number of issues, including gender, identity, age and so on. However, in this study I am interested in their experiences in relation to a curriculum.

- What is the nature of the palliative care curriculum in context?

In the final chapter of the study I answer this question theoretically by engaging data generated from the three questions above. In answering this question no new data are produced. It uses insights gained from data analysis to formulate a thesis for the study.

1.1.4 Significance of the study

This study is significant in several ways, which I make explicit below. The study is of importance in that it brings curriculum theory as a central focus in training of palliative care providers (specifically nurses). The training of nurses takes place on a platform of a curriculum and nurses and educators may or may not be aware of the curriculum theory underpinning this curriculum. In this study I make curriculum theory explicit.

Another value of the study is that, in a critical paradigm, it brings the experiences of the nurses into the foreground because these are shaped by factors which include a curriculum, and such experiences may be neglected in a positivist paradigm. The study is also important because I demonstrate how vital context is in applying any form of health science practice or intervention. An intervention, such as palliative care, is perhaps dependent on a context, and the study illustrates that context can make or confound an intervention. The study significantly illustrates how, through the voices of nurses, important information is available for curriculum designers, palliative care practitioners and for people who are interested in how health science education and practice can be improved.

In the study another important aspect is that palliative care, which has been generally studied in hospitals and hospices, is being studied in rural, isolated homes, and this study brings deep insights about what happens in rural homes. The challenges faced by nurses practising in rural homes are important to explore as some of these may be easy to negotiate and overcome by, for example, integrating these challenges into a curriculum which may make the work of nurses easier. While other challenges will remain a very harsh reality for which we really don't have answers, it is nevertheless important to know what these challenges are.

The study is important in showing how any curriculum and practice that originates in the North cannot be simply replicated and transported without any form of modification to the South. The study is significant because it explores the practice of palliative care in harsh, resource-deprived contexts and shows that palliative care can be successful in some instances, yet there are challenges which have to be acknowledged and negotiated.

1.2 An introduction to curriculum

A key aspect of this study is curriculum theory and the way we look at a curriculum. The way we theorize curriculum has altered over the years, and there remains considerable dispute around curriculum. The word has its origins in the running/chariot tracks of Greece (Pinar, 1974). It was, literally, a course to be covered. In Latin *curriculum* was a racing chariot; *currere* was to run. Many people equate a curriculum with a syllabus and a syllabus means a list of subjects or lectures, usually to be covered in a specific time frame. Jackson (1968) intimates that a curriculum is more than just a written syllabus and describes two elements for a curriculum: the “preactive” curriculum and the “interactive” curriculum. This study explores text of a curriculum as a preactive or espoused curriculum and analyzes practice of those who have experienced the preactive curriculum as an interactive or enacted curriculum; preactive can be regarded as the written curriculum text and interactive as the practice of an espoused curriculum. Maxine Greene (1971) has developed a dual notion of curriculum which furthers our understanding of Jackson’s curriculum distinction. She describes a dominant view of curriculum as a preactive curriculum as socially presented knowledge, outside the learner and there to be mastered.

In this study, a practice straddles an interface between a curriculum and a context. The practice is analyzed to explore a circumstance where a curriculum has been introduced into a context other than its context of origin. As such, the study presents neither a point by point analysis of a specific curriculum, nor an analysis of a specific context. Instead, using Vithal’s (2003, p. 114) notion of exemplarity,¹² palliative care practice in rural homes provides an example of a situation where a curriculum developed for one context is presented in another context. Palliative care curriculum is used as an example of how a context shapes, influences and challenges a curriculum in practice.

¹² I use the word exemplar in the same way as Vithal (2003, p. 114): exemplarity refers to selecting part of a system to try and understand a bigger problem. For example, using palliative care curriculum and practice in this rural, Southern context I try and understand what happens when a curriculum is introduced into a context other than its context of origin.

1.3 An introduction to palliative care

Another key aspect of the study is palliative care; palliative care is offered within an arena of healthcare, and within this arena care of patients is largely offered as a focused type of care within various specializations. Such specializations can be regarded as pertaining to either the part of the body cared for or the type of patient cared for, as I illustrate in Table 1.

Name of healthcare discipline	Focus of care
Cardiology	Heart
Pulmonology	Lungs
General Medicine	General physical care of the whole body
Geriatrics	People older than 65 years
Obstetrics	Pregnant women
Paediatrics	Children less than 12 years
Palliative care	People who have a life-limiting illness

Table 1: Healthcare disciplines and focus of care

Within a realm of health care it is not unsurprising that palliative care is offered as a special type of care that focuses on caring for a certain type of patient. An idea of palliative care began in the UK in the early 1970s and was introduced by Dame Cecily Saunders. Saunders originally set out in 1938 to study politics, philosophy and economics at St Anne's College, Oxford University. In 1940 she left to become a student nurse at the Nightingale Training School of London's St Thomas's Hospital (King's College London). Returning to St Anne's College, she qualified as a medical social worker in 1947. Throughout her career she considered the care of very ill and dying people to be poor and felt that the dying were neglected by healthcare professionals in hospitals. In developing an idea of palliative care, her intentions were to focus health care professionals' attention on care for people who faced death from an incurable illness. She considered that healthcare professionals ignored the dying and this reflected a tendency in society: society in general was considered to be "death-denying" (Ariès, 1974).

This situation in the UK can be contrasted with a situation in India. In the 1970s Mother Teresa became well-known internationally for her humanitarian work and advocacy for the rights of the poor, sick, helpless and dying. In India the culture was not death-denying, but it was fatalistic in accepting death and the dying were ignored for other reasons: a family could not afford to care for a dying patient.

Dame Cecily Saunders considered that any society that shuns the dying is lacking in some way (Saunders, Summers & Teller, 1981). Doyle, Hanks and McDonald (1998) believe that with the explosion of medical knowledge and technical ability to both diagnose and treat serious illness, there was a swing away from patient-centred care, and they imply that palliative care acts to counter-balance a lack of patient-centred care which they associate with technology. Their concerns arise from circumstances when, in a technologically-rich environment, a health professional may pay more attention to machinery surrounding an ill person than to the person. In the North the death of a person was often seen as a failure and as such health professionals did all they could to prevent what they regarded as a failure. This situation led to its own problems, for example:

This fear and denial within our society has lead us to ignore
or minimize the huge and rapidly growing burden of suffering
imposed by terminal illness. Our fear of death has dictated our
society's massive expenditure on high-technology resources in the
last few months of life in frantic, futile efforts to prolong life
(Scott, 1994, p. 36).

Problems associated with prolonging life at all costs can pertain to issues including the cost of care, as healthcare is generally expensive and prolonging life at all costs may be regarded as a futile use of limited financial resources. Selman (2007) is of the opinion that understanding and taking into account the many factors which professionals, families and, more rarely, patients “hide behind” to avoid the reality and challenges of approaching death, is a key component of any palliative care training. This author implies that health professionals “hide” from an inevitability of death and palliative care training aims to acknowledge and counter-balance a tendency to prolong life when a disease probably is incurable.

When a healthcare professional hides from death her patients may be disadvantaged, for example by being shifted to areas where they are not visible such as an isolated room. A doctor may request a nurse to deal with dying patients as the doctor feels she cannot cope with this issue as there is a loss of hope, and care may be perceived as unsuccessful. Nurses in turn may not want to care for dying patients and may make themselves “too busy” to interact with the patients or their relatives.

Palliative care aims to make dying transparent, open and accepted. In making dying transparent there is initiation of dialogue between healthcare providers, patients and families. Palliative care invites patients and families to gain awareness of the futility of continued medical intervention and invites patients to be part of the decision-making processes. It specifically aims to reduce suffering, which may involve coordinating confusing aspects of care when care is provided by many doctors who communicate little with each other.

Dame Saunders was instrumental in developing the world’s first purpose-built hospice, St Christopher's Hospice. The hospice was founded on her principles of palliative care and combined teaching and clinical research and expert pain and symptom relief to meet the physical, social, psychological and spiritual needs of its patients, who faced an incurable illness. The hospice extended care to family and friends, and this continued after the patient had died (Saunders *et al.*, 1981). Following on the work of Dame Cecily Saunders there have been dramatic reforms in the care of the dying, which have been widely positively acclaimed and, in a relatively short time, palliative care services and hospice facilities became available throughout the world (Singer & Bowman, 2002). Palliative care has developed as a distinct academic medical and nursing specialty in many developed countries, including the UK, the United States of America (USA), Australia, Canada and New Zealand (Charlton & Currie, 2008). In these countries palliative care is generally provided by an interdisciplinary team which can include a doctor, nurse, social worker, psychologist and spiritual counselor. Palliative care is provided mainly by healthcare professionals in hospitals, hospices, old-age home and in patients’ homes.

In Africa, where this study is set, palliative care services have been developing in a hap-hazard way and “*whereas the number of palliative care services is increasing rapidly in industrialized countries, the extent of establishment of palliative care programmes is believed to remain at a dramatically low level in developing-world contexts*” (Clemens, Kamar, Klaschick & de Lima, 2007, p. 174).

Some note that a rationale for palliative care development in the South lies in relieving the suffering of those who have cancer and Human Immunodeficiency Virus (HIV):

Palliative care mainly sprang from an identification of Suffering and urgent need to meet the needs of, initially people with cancer, and in more recent years those with HIV and AIDS (Merriman & Kaur, 2005, p. 1909).

Literature implies that palliative care has been introduced into the South as healthcare professionals in the South turn away from patients who face death:

In South African health care, the present focus on cure led to health care professionals turning away from patients for whom cure is no longer possible and abandonment of patients with far advanced illness to their families or compassionate caregivers ... There appears to be denial of the fact that, at the end of life there are often serious and distressing symptoms that require skill and expertise to control, and a need for emotional and spiritual support to promote physical comfort and allow dignity at death. (Gwyther & Rawlinson, 2007, p. 559)

This view resonates with those that palliative care is necessary as health care professionals are generally “death-denying” and tend to ignore or shun patients who face death.

Caregivers, who formed participants in this study, work in rural homes in the province of KwaZulu-Natal, South Africa. Palliative care was introduced in South Africa following a visit by Dame Saunders in 1982. Its development has been largely spearheaded by the Hospice Palliative Care Association of South Africa (HPCA), although palliative care is not a recognized medical or nursing specialty in South Africa.

The World Health Organization (WHO) has been active in promoting palliative care in Africa and the 'African Project on Palliative Care' is described as:

A Community Health Approach to Palliative Care for HIV and Cancer Patients in Africa which is a joint project among five countries - Botswana, Ethiopia, Tanzania, Uganda, Zimbabwe – and the World Health Organization (country, regional and headquarters offices). The main goal of this project is to improve the quality of life of HIV/AIDS and cancer patients in sub-Saharan Africa by developing comprehensive palliative care programmes with a community health approach.
(WHO, 2004, p. 1)

The APCA has also been instrumental in advancing palliative care services and education throughout Africa (APCA, 2011). However, in the context of this study, in the province of KwaZulu-Natal, palliative care services and education have been slow to develop. There is no Department of Palliative Care at the local University of KwaZulu-Natal, nor is there a designated palliative care programme within the District or Provincial Departments of Health. A study on a curriculum for palliative in Africa seems appropriate in 2011 as literature advocates for the expansion of palliative care education in Africa; the Palliative Care Trainers' Declaration of Cape Town 2004¹³ highlights a need for palliative care education (Sebuyira, Mwangi-Powell, Perera & Spence, 2004). This need for increased palliative care education is set against a backdrop of HIV, cancer and other diseases which may shorten life. In 2011 Grant, Downing, Namkwaya, Leng and Murray noted that while there has been much progress around palliative care in Africa, there is still a long way to go.

¹³ The first meeting of palliative care trainers in Africa was held in Cape Town in 2002. Thirty participants attended from five different countries: Kenya, South Africa, Uganda, Zimbabwe and Tanzania. A recommendation was that palliative care should be provided at all levels of health care (primary, secondary and tertiary). Primary care may be considered as including home-based and clinic care.

1.4 Introduction to rural homes

A third key aspect of this study is context, and the context is rural homes in KwaZulu-Natal, South Africa. Palliative care originated in the North and has been introduced into the South, and the South contrasts in many ways with the North. For example, some people in the South, such as elderly, rural people may not have been exposed to the world of medicine and health science. They may not have been to school and may have little access to televisions or computers. Indigenous/traditional¹⁴ people may have their own unique beliefs about illness, dying and death. Rural, traditional people may have few opportunities to map onto¹⁵ Western medicine and may not “know” what a type of care like palliative care offers, and palliative care may not be regarded as a discrete entity.

Alternatively some people may be aware of medicine and unquestioningly accept decisions made on their behalf and if a decision is made then they will not try anything else. They will not question a medical diagnosis and prognosis even if they do not agree or do not believe in it. In the South some people may not be sure that health or medical care is what they require; they may perceive that they need economic care as they may be starving. They may not have access to up-to-date medical intervention. Hospitals may be poorly equipped and doctors and nurses greatly over-burdened, and as a result people who would be hospitalized in the North may have to be cared for at home in the South. Home care may be very necessary in the South, as patients may have no other option of a place of care.

In particular, in South Africa hospitals are inaccessible as they are over-crowded since healthcare personnel are faced with a high burden of disease due to Acquired Immunodeficiency Syndrome (AIDS) and associated diseases. When a decision is made to offer palliative care the doctor, nurse or patient may not have had access to potentially curative intervention, diagnostic or prognostic tools which would be available in the North. Palliative care may have to be different in the South as it will have to consider the issues raised above, and a question must be explored around what role palliative care has to play in improving this situation.

¹⁴ By the term indigenous or traditional, I refer to any ethnic group that lives in a country or in a geographical area, and these people are the earliest known individuals to ever live in this place. For example, the Native Americans were indigenous to the USA because they are the earliest known inhabitants.

¹⁵ By the term “map on to” I mean understand or make sense off.

Palliative care may be challenging since caregivers at a rural, isolated coalface may be placed in a dilemma where they are unsure of prognosis or diagnosis, and their patients may be completely reliant on them for care.

Palliative care has been developed in the North, which represents a different context for training and practice, which take place largely in hospital and hospices. Palliative care ideas may not have a universal quality but may be conventions generated through countless decisions of people living in societies where people may have agreed when care becomes palliative care. Palliative care curriculum designers who work in a healthcare context in the North may be clear around how palliative care is conceptualized, what it wants to achieve, and how it will be received and valued.

Palliative care has been introduced into homes in the South and this represents a new context for training and practice. In a rural home, where perhaps there is no doctor, there may be an assumption that a trained nurse will be available to either offer palliative care directly or support others who offer palliative care. There may be an assumption that a diagnosis is available, and in practice a caregiver may not know what is causing a problem. A rural caregiver may offer palliative care without knowing what is wrong or how long a patient is expected to live. A situation could arise where palliative care may be the only type of care offered and may not be appropriate for the disease or condition, or aspects of care may be offered at an inappropriate time. Certainty around diagnosis and prognosis may be assumed in a hospital, and yet such certainty may become disrupted in isolated, impoverished homes.

Some patients may be grateful for information about her illness; however, do all people want information about their illness and do they wish to be included in decision making? Can we be certain that palliative care is something which people at home value? Caregiving does not operate in a health science vacuum as patients have cultural beliefs, religious beliefs, hopes and dreams that go beyond health care. A palliative care curriculum may be certain that ways of caring are a “right” way, and in such certainty the curriculum may inadvertently ignore or devalue other ways of caring. For example, a curriculum may espouse that it is best to tell a patient that they face death due to an illness, and yet the patient and family may prefer not to know. Alternatively, a caregiver may be administering palliative care without being exposed to a curriculum and without knowing that what she offers is palliative care. In this study I will show how a context can undermine a notion of certainty in curriculum.

1.5 Structure of the study

As I have alluded to previously, this study comprises five parts.

Part One: Introduction: Researching palliative care curriculum in rural homes

This part provides an overview of the study and orients the reader to curriculum, palliative care and a rural, home context.

Part Two: Landscapes of palliative care, curriculum and rural homes

In Part Two I aim to deepen the reader's understanding of the three key aspects of this study. First I provide an overview of literature on palliative care theory and practice, and in attempting to understand the discourse around it I draw on its definitions and highlight debates and tensions. Secondly, I provide an overview of curriculum theory and juxtapose curriculum theory with palliative care curricula. Thirdly, I provide an overview of healthcare in rural homes within the context of this study.

Part Three: A paradigmatic and methodological foray

In Part Three I introduce the reader to critical and post-structural paradigms and to data collection methods. Throughout the study I use an idea of generativity and invite the reader to apply insights gleaned from this study to their own context. I am not focused on issues such as generalizability and a "correct" interpretation of data. I request palliative care practitioners, researchers and curriculum designers to abandon quantitative hats. Any interpretation of data involves a process of inclusion and exclusion and is, by definition, partial and open to contestation. Hence the issue is not whether my data interpretation is true or false, rather am I able to open opportunities for the reader to think about curriculum in a new way? This study considers what is the change in context between the North and the South and what meaning does this change have on practice of palliative care. The study invites the reader to ask questions in their own context. Can a curriculum prepare learners if the context is blurred and fuzzy? Is curriculum trying to prepare learners to know all the answers when answers are unknowable?

Part Four: Working with data

Here I look at the first three of the study questions. For study question number one I present data on a preactive written palliative care curriculum as a source of knowledge for participant caregivers who practice palliative care in rural homes. For study question number two, as a form of an interactive curriculum, I present data of caregivers' experiences of their context, and for study question number three I analyze data relating to their experiences of palliative care practice. To deepen the reader's understanding of data I juxtapose findings from this study with published literature as I make meaning of findings within a broader context. Throughout this study, I am in no way suggesting that palliative care providers do not care; I am suggesting that care may be beyond the capacity of palliative care. An ability to practice palliative care may be hindered by systematic problems and structural issues. It may be that inability to practice palliative care may not be the fault of a curriculum, as a curriculum developed in one context may comprise tried and tested procedures and methods that work in that context. The further one moves away from the origin, the more a context may change, and a certain curriculum may become disrupted and fragmented.

Part Five: The thesis

In Part Five, which is the thesis, I look at study question number four. As I try to make meaning around a curriculum, practice and context, I find that I must alter my lens of enquiry from critical to post-structural. Carl R. Rogers tells us that "Life, at its best, is a flowing, changing process in which nothing is fixed" (Rogers, 1961, p. 27). I explore curriculum as a flowing, changing process in which nothing is fixed. Things which are certainties in a preactive curriculum may become destabilized when practicing in context. I reach a thesis around certainty and curriculum and practice in context.

The literature notes that palliative care is currently placed largely within a health science arena (Zimmermann, 2007). Health science may neglect some subjective issues (such as ignorance, prejudice and poverty) which may influence palliative care. Science tends towards objectivity and towards certainty, and striving towards certainty in science can be traced back to the work of Descartes and Newton.

The former advocated rationalism while the latter unearthed a collection of fundamental laws. Following on the work of Newton, a flood of other discoveries in diverse fields such as magnetism, electricity, astronomy and chemistry soon followed, injecting a heightened sense of confidence in the power of reason and certainty to tackle any situation, including health care. By the late 19th and early 20th century many scientists believed that few surprises remained to be discovered and, more fundamentally, the assumption and expectation was that over time the orderly nature of all phenomena would eventually be revealed to the human mind. Science became the search for hidden order.

By and large, that vision of the universe survived well into the twentieth century. In 1996 John Horgan published a bestselling book *The End of Science*, which argued that since science was linear and all the major discoveries had been made, then real science had come to an end (Horgan, 1996). He felt that certainty and predictability, the hallmarks of an orderly frame of mind, were too good to last. Recent thinking around striving for certainty in science do not disprove Newton but reveal that not all phenomena are orderly, reducible, certain, predictable and determined (Hardy, Sackett, Doherty & Adams, 2011). For example, consider light and two theories around the nature of light. One theory advocates it as a particle and a second theory advocates it as a wave. No matter how hard classical physicists tried, they could not define light as either a distinct particle or a wave, it is both. The dualistic nature of light as both a wave and a particle contradicts science's orderly, classical system, and what this means is that even at the most fundamental level there is still theorizing in science when one theory can be regarded as more plausible than another. The boundaries of a classical paradigm of certainty are cast asunder; gravity continues to function and linear mechanics continue to work, but science can no longer claim to be universally applicable to all physical phenomena. Science has to live alongside phenomena and theories that are at most probable. Foley (2010) eloquently describes a duality in nature:

At first the atom was only a nucleus surrounded by electrons and only electrons were weird like a modern bisexual, it could be a particle one moment and a wave at the next, depending on who was making eyes at it. This was disturbing but at least the nucleus was dull and dependable as a GP in a market town. Then the supposedly solid nucleus was found to be teeming with particles. It was a particle zoo (Foley, 2010, p. 217).

I provide no recommendations for the reader, and reasons for not making recommendations will become self-evident. The study is not satisfied with the current curriculum or practice of care; I attempt to refine both curriculum and practice by looking at a tripartite of curriculum, context and practice. At times, in what follows I will be pointing to muddles and fuzziness, and I do so in order to advance palliative care through a curriculum, to work on it and perhaps to improve it. The study focuses on context, curriculum and practice and as such may be different to other studies which a doctor, nurse, or curriculum theorist will read. Aspects of it may be unsettling. Usually the word unsettling has negative connotations, as it speaks of uncertainties and discomfort. I use the word in a positive sense as I hope to open windows of opportunities for the reader to view the palliative care curriculum in a new way. I wish to alert the reader to a possibility that a curriculum may not be readily translated and achieved to benefit everyone. A curriculum may need to be shaped by scepticism, surprises and uncertainty in context.

1.6 Conclusion

Part One, Chapter One served as an overview of the study and is required to orientate the reader to the rest of the study. The study is specifically interested in those who have experienced a curriculum which has been introduced from a context of origin to another context, and uses a curriculum of palliative care as exemplar.

The purpose of part one, chapter one was threefold. Firstly, I highlighted views that health science represents one way of looking at the world and there are strikingly different ways of looking at and interpreting the world. Part One provided a brief overview of the ethos of qualitative research and I highlighted that such research focuses on the lives and experiences of participants in their own context. Such research can make no claims to generalizability or replicability, and requires its own criteria for understanding or validity. Positivism, generally associated with science (including health science), favours issues such as generalizability, reliability, replicability and validity and considers that the world can be predicted. In qualitative research paradigms give differing ways of looking at the world, and rigour in qualitative research seeks criteria such as authenticity, trustworthiness and generativity. The study considers that curricula in health sciences are generally not based on a foundation of curriculum theory but rather on foundations associated with positivistic methods such as laboratory work and controlled experiments. A significant aspect of this study is a focus on curriculum theory.

Secondly, in providing a rationale for my interest in a palliative care curriculum I recounted three stories of people requiring care in differing contexts. A specific aim of these stories was to illustrate how people can be placed in multiple contexts and can experience multiple ways of receiving and providing palliative care. As a junior medical student, family member and qualified doctor I have experienced care of those who face death in hospitals, hospices and in rural homes. Parts of caring in differing contexts may be similar and others dissimilar or even invisible. This study focuses on palliative care provided by nurses who work in rural homes.

There are many significant aspects to this study; in particular, in a critical paradigm the voices of those who practice palliative care are fore-fronted. In this study a method gave participants freedom to illustrate what was important to them. A critical paradigm was employed since a palliative care curriculum which does not consider context may be oppressive.

Thirdly, it was necessary to provide a brief overview of curriculum, palliative care and context. Curriculum is regarded as more than a written text containing subjects and lectures. An interactive curriculum considers how a written or espoused curriculum is experienced while practising in context. Palliative care developed in a Northern context and the ideas of palliative care may represent ways of thinking within this context. Within a Northern context palliative care was seen to be necessary as doctors and nurses were thought to care poorly for their patients who faced death. Doctors and nurses were not comfortable with caring for dying patients and palliative care aimed to assist healthcare professionals to have empathy for and to include patients and their families in care decisions. In the past palliative care was taught and practised largely within hospitals and hospices and the Cape Town Palliative Care Trainers' Declaration intimated that palliative care should be provided in primary settings (including patients' homes). In many ways a context of rural homes differs from that of hospitals and hospices.

It may be that things which are certain in one curriculum context may become disrupted in another context. For example, we may be certain of a patient's diagnosis in a hospital, but an isolated caregiver cannot be certain of a diagnosis at home. Science has needed to consider challenges of uncertainty, and in the final part of this study I provide a theoretical explanation for a need to consider certainty and uncertainty when delivering a curriculum in context.

In the following part I expand on an idea of palliative care and on curriculum, and provide an overview of healthcare in rural homes as I see a need to deepen the reader's understanding of these issues.

PART TWO

A LANDSCAPE OF PALLIATIVE CARE, CURRICULUM AND RURAL HOMES

Part Two can be regarded as deepening foundations for the study and comprises three chapters. In the first of these chapters, in order to deepen the reader's understanding of palliative care, I review theories and practices. I present challenges in defining palliative care, and tensions and debates around how it is situated within a healthcare and broader social arena.

The second chapter focuses on curriculum theory and presents an overview of four types of curriculum: technical, practical, emancipatory and autobiographical. I locate current palliative care curricula within these types of curriculum.

The third chapter is aimed at providing the reader with knowledge around a particular kind of socio-cultural context - rural homes.

CHAPTER TWO

A landscape of palliative care

2.1 Introduction

Palliative care developed in the UK in the 1970s. These dates are when the notion was labeled and I do not suggest that palliative care was not carried out prior to this. Pastrana, Junger, Ostgothe, Eisner and Radbruch (2008) carried out an extensive analysis of palliative care literature and concluded that although there is a lack of consistent meaning around definitions and terms in palliative care discourse, the main goals identified are the relief and prevention of suffering.

Patients who are offered palliative care are those who face a life-limiting illness, and palliative care can be offered in hospitals, hospices or at home. Earlier I illustrated that some believe palliative care to be valuable because society is considered to be generally death-denying and patients have the right to be given information and to be involved in decisions around care. In the North literature illustrates that an idea of palliative care is not fixed and there are ongoing debates around it, for example:

Is palliative care end-of-life care? Or is it broad and integrated physical, psychological, social, and spiritual care for patients with serious diseases that may be life-threatening? ... Some believe that palliation and cure are not mutually exclusive and that palliative care should be practiced during all stages of serious illness, even while aggressive curative treatment continues. The exact point at which a patient's palliative care begins remains a subject for discussion. (Fox, 2002, p. 1).

The above quotation illustrates that there is no consensus on aspects of palliative care, for example when it should be offered.

A study carried out in a United States hospital concurs that there is some ambiguity around caregivers' experiences in palliative care and in finding "the true dying point":

Most participants viewed palliative care as a changed dimension of care that is instituted once it is known that a child is dying. Three challenges in employing palliative care to acutely ill infants and children were identified: (a) finding the true dying point, (b) making the transition to palliative care, and (c) turning care over to an outside palliative care team at a critical juncture of caring (Docherty, Miles and Brabdon, 2007, p. 335).

Literature illustrates that some aspects of palliative care, such as knowing when the patient is dying, present complex issues for the hospital-based caregiver. Such challenges may be magnified in a home when a caregiver has little or no access to diagnostic or prognostic equipment. In her editorial, Carole Tishelman alludes to complexities in palliative care:

And indeed, there is much to reflect over and much to discuss and debate ... Tensions between empirically-generated evidence and experiential knowledge need to be dealt with - what forms of knowledge should be acknowledged as relevant in palliative and end-of-life care? How can they complement one another? And when do they clash? (Tishelman, 2007, p. 4).

Palliative care is complex, and in this chapter I delve deeper into palliative care and consider literature which may be relevant for palliative care curriculum designers working in an African context. I open with an attempt to define palliative care as curriculum designers will perhaps need to translate palliative care from English to African languages. I then review a view that palliative care is required for caregivers, as they feel distressed when dealing with dying patients; curriculum designers may need to be particularly aware of the distress faced by caregivers in Africa against a backdrop of the enormity of the HIV and AIDS epidemic.

I then present a brief review of a debate around palliative care being necessary in a Northern context because society is death-denying, since curriculum designers may need to take cognizance that not all societies may be death-denying. I review literature around palliative care as a specialist type of care since this discussion has implications for home delivery of palliative care. Finally I look at palliative care beyond health sciences, since curriculum designers may need to review palliative care within a space beyond healthcare as there are views that palliative care can perpetuate social injustices.

2.2 Palliative care: Troubling definitions

In this section I look at definitions for the term “palliative care”. A palliative curriculum would need to provide some explanation around the meaning of the term and a curriculum in South Africa may need to scrutinize definitions of terms closely as English is not the first language of most people in rural areas, and English may have to be translated into African languages. The most commonly used definition of palliative care is provided by the WHO:

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-limiting illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 1990).

As I stated earlier, the WHO has been active in promoting palliative care throughout the world and particularly in Africa.¹⁶ The WHO definition places palliative care within a field of healthcare, as the people who receive care are referred to as patients.

¹⁶ In the early 1980s, the WHO Cancer Unit began the development of a global palliative care initiative which advocated for pain relief and opioid availability worldwide (Sepúlveda et al., 2002).

The WHO advocates that:

The principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness.

This change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease (Sepúlveda, Marlin, Yoshida & Andreas, 2002, p. 92).

The WHO defines who should receive palliative care: anyone with a chronic and ultimately fatal illness. In general, healthcare professionals can be largely sure of who should receive their care. For example, a geriatrician can be sure that she cares for patients over the age of 65 years. A pediatrician can be sure that she cares for children who are less than 12 years of age. Can a palliative care practitioner always be certain that her patient faces a life-limiting illness, chronic and ultimately fatal illness? In rural South Africa a woman who has had cervical cancer may visit a hospital which is far from her home. She may receive treatment and return home with no record of the treatment and this is not an unusual scenario. The home-based caregiver in some instances may not be able to access information about her patient's medical condition and so cannot know if the cancer is cured or in remission or at an advanced stage, and cannot be sure from which base to operate.

2.2.1 Palliative: Excusing, concealing and softening

In seeking to understand palliative care using definitions, I look at the origins of the word palliative; *Webster's Dictionary* defines the word *palliate* as:

To cover with excuse; to conceal the enormity
of offenses by excuses and apologies; hence, to extenuate;
to lessen; to soften by favourable representations; as, to palliate
faults, offenses, crimes or vices. To reduce in violence; to
mitigate; to lessen or abate; as, to palliate a disease.

To palliate could be regarded as giving excuses or hiding something by presenting a favorable representation or lessening or abating. As such palliative care could be regarded in a negative light as hiding something or presenting a favourable representation of something bad or vulgar. Care of the dying could be reviewed as vulgar in a medical worldview that sees “good” care as cure, and a concealing type of care could be offered when the nature of care changes from saving life to sustaining life or preparing for death. This definition of palliative could hold somewhat deleterious connotations around care; the very use of the word has implications.

2.2.2 Palliative: Cloaking

Further exploration of the word *palliative* locates it in Latin, and *The Oxford Dictionary of English Etymology* indicates that the word derives from the Latin word *pallium*; a cloak or a shroud (Hoad, 1986). There could be at least two interpretations of the word cloak. In ancient Greece and Rome men draped a *pallium* over their left shoulder and around the body, and as such a *palliate* or cloak could be regarded as sheltering or comforting.

However, another view of the cloak places it in terms of concealing. Palliative or cloaking could be viewed as a euphemism for something unpleasant or vulgar. Rallison and Moules (2004, p. 289) discuss cloaking of one’s emotions as a negative way of caring when healthcare professionals deal with a dying patient or the relatives of a dying patient:

Cloaking also raises the issue of keeping something covered or hidden and how there are things that nurses prefer not to see in families and things they choose not to see. ... A single mother and four children moved to the city from a rural community as one of her children was diagnosed with a very aggressive cancer and would be in and out of hospital frequently. Through her outspokenness and lobbying for her child, the mother became labeled as difficult and challenging. There was a distancing by staff members, indicating a desire to remove themselves from much involvement with the child or the mother.

It may be difficult to understand the concept of palliative care as cloaking. Cloaking may be a negative experience in which caregivers try and keep something unpleasant, such as a perceived difficult patient, at arms' length. Cloaking may also hold negative connotations as the aim of a cloak may mean to cover up or deceive (Morris, 1998).

2.2.3 Palliative: Shielding

Morris (1998) argues that the word *palliate* should not be viewed as a cloak and should rather be seen from an Indo-European linguistic tradition in which the term palliative is derived from the verb *pelte*, to shield. He states that the word “*shield avoids a pejorative sense of passivity in human action*” (Morris, 1998, p. 230). In contradiction to Morris' assertion that a shield avoids a pejorative sense of passivity, in being shielded from harm a patient is forced into a passive role.

Thus a notion of palliative care as a shield is neither empowering nor sensitive to patients' needs which remain unspoken, particularly in a context where patients are illiterate, marginalized and impoverished. To date there has been no consensus on the meaning of the word *palliate*. Both cloak and shield may depict the person requiring care as a passive recipient of the care, and neither word seems to allow for any involvement of the person requiring the care, and patient and family are rendered passive spectators in their care. These definitions are the antithesis to a view that palliative care empowers the patient and their family. It may be that practice of palliative care indicates a need to rename palliative care or redefine the term.

2.3 Palliative care: Necessary as caregivers are distressed

In this section I review literature that proposes that palliative care is required as caregivers become distressed when caring for dying patients. The underlying philosophy of palliative care may be thought of in terms of reducing distress and suffering among patients and their families (Karver & Berger, 2010), and literature also notes that it can reduce distress among healthcare providers who cope with patients who face death. Ways of helping caregivers cope with distress may be relevant in any palliative care curriculum, and in particular in an African home-based palliative care curriculum as caregivers may have to face large numbers of patients who have chronic illnesses such as HIV and AIDS.

During their career most health professionals, including nurses, will encounter patients who are at the end of their life, and caring for dying people and their families has been described as “*one of the most disturbing and potentially unpleasant roles that a nurse must undertake*” (Allchin, 2006, p. 113). White, Coyne & Patel (2001) concur that experiencing dying and death are challenging for nurses. Burnard *et al.* (2008) found that the most commonly reported stressors in nursing included the death of a patient or listening or talking to a patient about their approaching death, and that witnessing a death has a negative emotional impact on nurses. Deeny *et al.* (2001) concur that nurses who care for dying patients may experience painful emotions, distress, and sometimes feel threatened by the experience.

In a South African hospital context, Richter, Chandau and Rochart (2008, p. 199) described the experiences of nurses who care for very ill children who may face death, and note:

In addition to the personal impacts of HIV on nurses' lives,
The burden of medical care in the public health sector for
people living with HIV and AIDS has largely fallen on nursing
staff. As a consequence of all these factors, there is a high
risk of nursing burnout and compassion fatigue.

Govender, Rochart, Richter and Rollins (2006) note that in South Africa, set against the impact of the HIV/AIDS epidemic, nurses' experience of the ontology of nursing has changed; where previously the goal of nursing was health, recovery and cure, nurses are now faced with having to care for mainly dying people. The nature of nurses' knowledge required to care for the dying in hospitals in a South African setting has changed and many nurses noted that they do not have the skills for nursing the very ill and dying (Govender *et al.*, 2006). Palliative care may be a way of supporting nurses, as an ethos of palliative care is to support the caregiver (Doyle *et al.*, 1998). Palliative care services offer behavioural and cognitive coping mechanisms aimed at managing the demands of stressful transactions.

2.4 Palliative care: Necessary to counteract a “secret”

In this section I review literature around a view that Western society is characterized as “death-denying” (Ariès, 1974). Such a review is pertinent as a curriculum for palliative care in Africa may need curriculum designers to consider whether the society is generally death-denying. From the late eighteenth century onwards a tendency to withhold the prognosis of imminent death from the patient developed. Ariès (1974, p. 57) labelled this tendency to withhold a prognosis of imminent death as “*the lie*” and proposes that “*the lie*” dominated care of those who faced imminent death between the mid-nineteenth and mid-twentieth century. Connor (1998) holds a view that palliative care is required as society is generally “death-denying” and there is a ‘regimen of silence.’ To keep information around dying and death silent and a secret was justifiable because patients inevitably feared death and relied on the hope that “the secret” gave them. In this sense, silence was desired by both parties; doctors did not want to speak of death because it was distressing and distasteful, and patients did not want their worst fears confirmed. The secret could not be spoken and yet it could in mysterious ways pass between doctor and patient without speech (Connor, 1998).

Armstrong (1987) maintains that it was not only since the advent of palliative care that death has been exposed and he condemns a view that until the palliative care movement arose there was a regimen of silence. Armstrong challenges the “*argumentations of a ‘death-denial thesis’*” by asserting that since the mid-nineteenth century, rather than a silence on death and dying, there has been an explosion of discourses around these subjects with the moving of death from the private to the public domain. He notes that the death certificate can in this sense be regarded as a symbol of the visibility of death and the increased attention paid to the documentation of death and its causes. He maintains that with medicine (not specifically palliative care), what has changed is that a focus on the dying body changed to a focus on the dying person who is exposed to a penetrating power of medical interrogation.

In the North there has been a major shift from believing hope may be preserved in patients by keeping them ignorant of their condition, to believing that if they are to make their own decisions about what remains of their lives, they must be told the truth about their condition (Walter, 1994; Higginson & Costantini, 2008). Today, in many countries dying patients’ basic human rights are considered violated when they lack the knowledge and the power to make their own end-of-life decisions. Patients should have the right to know their condition and to have control over their dying processes (Kearl, 1989).

In palliative care death is constructed as something familiar and inevitable and something that should be talked about without embarrassment. Palliative care attempts to counteract a 'conspiracy of silence'. It could be argued, then, that death (from a palliative care stance) should be a public affair. Nonetheless, some critics (Williams, 2003; Somerville, 2001) assert that death is still largely hidden behind the walls of the hospital or, more recently, the hospice.

Other literature questions the view that societies are 'death-denying'. Kellehear (1984) disputes that there is a death-denying thesis at all. It is proposed that the fear and denial of death are staged as specifically modern and problematic, despite the fact that these are sentiments which have always existed (Elias, 1982). Terminally ill patients and their families are often referred to as being "in denial" of impending death, and Zimmermann (2004) illustrates that discourse on this theme is conflicting and at times self-contradictory and overall consistent with a "biomedical model" of illness. She suggests that what has changed over time is not our attitude towards death but rather our discourse surrounding that attitude. She says that:

Rather than being a defense mechanism at the level of individual psychology, denial can be seen as an instrument in a larger discourse on dying, which both invited patients to participate in the planning of their death and labels those who do not (Zimmermann, 2004, p. 1776).

Discourse around death denial may act as a way of labelling people and determining a "right way" to die. In a later paper Zimmermann (2007) suggests that palliative care discourse around death-denying has been integral to building and sustaining what is perceived as a correct "way to die". Earlier I suggested that in some cultures, such as Indian culture for example, society is generally fatalistic about dying; in this study I will use data to reflect whether rural Zulu society appears to be death-denying since this may impact on shaping a curriculum for home-based palliative care.

2.5 Palliative care: Necessary as specialist care?

In this section I explore whether literature locates palliative care as care provided by a “generalist” or “specialist” healthcare provider, as such reflection may be relevant when considering a curriculum around who delivers palliative care in patients’ homes. For example, if palliative care needs to be delivered by specialists then the number of people available to offer care in patient homes may be reduced. I open by explaining the terms generalist and specialist.

Within the healthcare arena patient care can be delivered by either generalists or specialists. A generalist, such as a General Practitioner, will care for whatever patient enters her surgery and will offer care for a wide range of diseases and conditions. If the General Practitioner feels that she is unable to assist, then she will refer to a specialist who has in-depth knowledge of a specific disease or conditions. Literature refers to palliative care in Africa as a “clinical specialty”:

Palliative care is a clinical specialty concerned with the management of the physical, emotional, social and spiritual manifestations of pain among those living with a life-limiting, incurable disease (Harding, Sherr & Albertyn, 2010b, p. 1).

“Clinical” can imply medicine but may also imply a sterile, controlled environment. Bradshaw (1996) warns of dangers in reducing care of seriously ill patients to bureaucratic, clinical, routine care. She is concerned that there is a risk that patients will become dehumanized if care is bureaucratic and clinical. Literature critiques whether palliative care should develop as a distinct medical, nursing, clinical specialization as some healthcare providers advocate that patients are disadvantaged by placing palliative care as a clinical specialty within a system where they perceive that healthcare services are largely defined by vertically distinct and rigid specialties. For example, in his article regarding palliative care and social justice, Selwyn (2008) warns that the rigidity of palliative care as a distinct medical specialty can have adverse effects on people and on health systems. I provide a specific example so the reader can make sense of his concerns: a young child with leukemia may go to visit an oncologist for chemotherapy. She has lost all her hair because of the treatment. While at the oncologist, she mentions that her ear is sore.

The oncologist refers her to a specialist ear, nose and throat specialist, who finds that her ear is normal. He may not see the child as a frightened, angry, anxious teenager who is worried that her friends may tease because her large ears are rather prominent and are uncovered as she has no hair.

Selwyn (2008, p. 514) states that it is critical for palliative care clinicians, educators and policy makers to examine the way in which the discipline of palliative care has arisen within a larger system of medical specialization. He is concerned that specialization in palliative care may run a risk of further contributing to fragmentation and undesirable outcomes, unless some of the underlying contradictions are challenged and overcome.

Earlier I presented literature which notes that caregivers express challenges when “*handing a patient over to a palliative care team at a critical juncture in care*” (Docherty *et al.*, 2007). If patients are referred to specialists when they need palliative care, then the referring doctor or nurse may potentially deny themselves an opportunity to come to know deeply about caring for a dying patient, and the patient may become confused as they face another caregiver. However, it may be that a palliative care specialist team can provide a fresh way, with in-depth knowledge around planning and coordinating patient care.

2.6 Palliative care: Beyond health care

In this section I review that healthcare does not operate within a vacuum and present literature which explores palliative care within a broader societal viewpoint. Such a review is necessary for palliative care curriculum development as curriculum designers may need to consider whether African society may show convergence or divergence from views around palliative care and social justice. Some hold a view that palliative care, particularly in resource-poor settings, can lead to a relative emphasis on the incurability of a disease and in doing so detract attention from other forms of care:

Palliative care’s relative inattention to disease prevention and cautious attitude to disease modifying treatments, however justified in resource-rich settings, is not justified in resource limited areas where such interventions could relieve needless suffering and prevent needless death among the poor (Krakauer, 2008, p. 506).

The context for this sentiment lies in a belief that palliative care generally does not advocate for accessibility to antiretroviral therapy (ART).¹⁷ ART is required for people who have HIV disease and can act to prolong life, and if ART were universally available it would relieve suffering and prevent needless deaths. Krakauer challenges us with a simple yet profound statement:

It is unethical, unjust, and unacceptable to promote or condone a global system, which in effect offers disease-modifying therapy to the rich and palliative care to the poor. (Krauker, 2008, p. 505)

The logic in the above quote is that by overtly focusing on non-curative interventions, palliative care could be regarded as denying the poor curative interventions which are only available to the rich. Palliative care may be regarded by some as an affordable alternative to other, more expensive medical treatment. The role of palliative care within a society which has been decimated by HIV and AIDS has been questioned.

As an example, Bollini, Venkateswaran and Sureshkumar (2004) believe that in light of the prevalence of HIV, AIDS and cancer and the difficulty and complexity of making treatment available to all who need it, palliative care has been proposed as a more achievable and affordable alternative to disease-modifying (or curative) treatment for HIV, AIDS and cancer in resource-poor settings. Some people may regard palliative care as a form of ‘false charity’. Freire describes false charity as a charity which gives a little to the extended hands of the have-nots, but preserves the power of those who have power (Freire, 1972)¹⁸. In a vein of false charity, palliative care can be viewed as helping poor people die with less pain because that is more cost-effective and feasible than helping them to live.

Some do not find a concept of palliative care to be of use, and indeed view it with suspicion; in America a well-known community leader asked if palliative care was just a way for African-Americans to get comfortable with dying (Krakauer, 2008, p. 506).

¹⁷ Antiretroviral therapy is medication specifically designed for patients with HIV/AIDS. The medication will stop the virus replicating but will not remove it completely from the body.

¹⁸ Social justice is defined as a just distribution of goods within society and examines the relationships between groups and individuals that influence the distribution of goods. Such work entails advocating both for the poor on an individual level and for solutions to the structural barriers that deny them access to affordable, adequate care, such as health care. As educator and theorist Paulo Freire puts it, “True generosity consists precisely in fighting to destroy the causes which nourish false charity”. A social-justice approach would nourish “true generosity” for which Freire argues. Freire would question why palliative care does not promote distribution of antiretroviral therapy.

The context for suspiciousness around palliative care arose from experiences of the African-American community where there was a vulnerability to untimely death, ostensibly due to violence, denial of health care, second-class care, abuse in medical research projects and physician-assisted police activities. Palliative care could potentially perpetuate social injustices.

2.7 Conclusion

I concur with Carole Tishelman (2007) that there is much to reflect over in palliative care. Palliative care is complex, and a common thread in palliative care discourse is an intention to relieve and prevent suffering although terms and definitions are not consistent. Definitions used, such as the WHO definition of palliative care, may make assumptions that who has a life-limiting, chronic and ultimately fatal illness is knowable. A review of the meaning of the term “palliative” reveals that its meaning can appear to be somewhat contradictory to what palliative care aims to achieve, as defining care as excusing, shielding or cloaking diminishes any potential empowerment of the patient and family.

A palliative care curriculum may need to consider that ideas in palliative care may make assumptions around issues such as a “death-denying thesis” and that palliative care providers act to counteract a death-denying society by making dying open and by empowering the patient, the family and the healthcare provider to jointly plan ongoing care. This has implications for this study as curriculum designers in Africa may need to be aware that ideas around a need for palliative care are not uniform, there is opposition to the idea that palliative care is required because society is death-denying, and there is a view that palliative care may act to label a correct way to die. Palliative care curriculum designers may also need to review that there is debate around whether palliative care should be regarded as a specialist discipline, and that some regard the notion of palliative care with some suspicion as they view that it may perpetuate social injustices among the poor, marginalized and oppressed.

Palliative care developed in the North and has been introduced to the South relatively recently. I based the questions for this study around the knowledge source and experiences of caregivers who practice palliative care in a rural home context. This seems an opportune time to review a situation where a curriculum developed in one context is introduced into a new context, since the practice of palliative care at home in Africa is in its infancy.

CHAPTER THREE

A landscape of curriculum

3.1 Introduction

This study foregrounds curriculum theory and a focus is on a specific curriculum used to train nurses for palliative care in South Africa. This curriculum is used as an example of a situation when a curriculum is introduced into a context other than its context of origin and I will describe the nurses' palliative care curriculum in-depth in Chapter Seven. In this chapter I focus on curriculum and provide an overview of ways of looking at curriculum. I provide an overview of definitions of curriculum and then focus on palliative care curriculum. I hone in on palliative care at home, and this is followed by a brief discussion on benefits and challenges of a curriculum for palliative care. I locate current palliative care curricula, which have been developed within a Northern milieu, within four curricula types: technical, practical, critical and biographical. My aim is not to provide an in-depth overview of curriculum, since in this study the focus is not on a curriculum but rather on what happens when a curriculum is introduced into a context other than that where it originated.

3.2 Defining curriculum: An overview

There is no single accepted definition of curriculum (Graham-Jolly, 2003). At a general level, definitions of curriculum may be either narrow or broad in relation to what is included and excluded in any given statement. For example, a curriculum that refers only to a syllabus is a narrowly defined curriculum. By a syllabus I mean a written text which supplies a list of topics to be discussed or lectures to be delivered. Since the 1980s a trend has been set in defining a curriculum more broadly than simply a written, predetermined syllabus to be followed. For schools a curriculum can be regarded as comprising all the opportunities for learning provided by the school. This includes the formal programme of lessons in the timetable, attitudes, styles of behaviour and the general quality of life established in the school community as a whole (Department of Education and Science, 1980).

A broadly defined curriculum can become a complicated conversation. In this study I take a view of curriculum beyond a written syllabus which merely lists predetermined topics to be covered over a period of time. I see a curriculum as a broad landscape for learning opportunities.

3.3 Palliative care curriculum provision: An overview

I provide a general overview of palliative care curriculum and education which is considered to be a key component of palliative care (Stjernswärd, Foley & Ferris, 2007). In this study my interest in nurses' curriculum underpins my interest in a home care context since, as I explain shortly, nurses form the majority of healthcare professionals providing palliative care in homes. In the North the literature notes that nurses play an important role of providing palliative care:

Of all the healthcare professionals, nurses typically spend the most time with patients and their families and are uniquely trained to serve as clinicians, advocates and educators. Furthermore, they provide care across the life span, throughout the disease trajectory, and in virtually every healthcare setting, including inpatient, outpatient, home care and many others. As a result they have the greatest potential to change the way care is provided to those with life-threatening illness.
(Paice, Ferrell, Coyle & Callaway, 2008, p. 173)

In the USA the End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative aimed at improving end-of-life care. The project provides training for undergraduate and graduate nurses and also provides development for educators so they can teach palliative care to other nursing students and practicing nurses. The project, which began in February 2000, considers previous needs identified by nurses who care for the dying (Ferrell, Virani & Malloy, 2005). The ELNEC calls for collaboration between the USA and international partners.

There are an increasing number of palliative care courses for nurses in Europe and a wide range of courses that attract not only the interested beginner but also the experienced practitioner (de Vlieger, Gorchs, Larkin & Porchet, 2004). However, despite availability of palliative care courses, a need to educate around palliative care was reiterated in 2007, when a review noted that there was a tremendous ongoing need to educate professional nurses and other health care providers in care for the dying (Meyers-Schim & Raspa, 2007). Despite a belief that palliative care education is necessary, there appears to be a general scarcity of education opportunities where new skills can be acquired and existing knowledge consolidated (Koffman, 2001). The situation does not appear to have changed over time, and it is noted that what little research exists suggests that death education or end-of-life teaching is severely lacking within nursing schools and has been for many years (Carson, 2010).

Literature on palliative care curriculum for nurses and other caregivers who provide care at home in Africa seems to be largely absent. In one study in Uganda nurses were requested to list particular skills which they identified as necessary in order to practice palliative care for young children. They identified that they had educational needs such as “technical” skills (such as delivering medication) (Amery, Rose, Byarugaba & Agupio, 2010). The researchers felt that the nurses actually required “non-technical” skills (such as listening skills), and there was a disparity between what the nurses believed they needed and what the researchers believed they needed. The gaps in the literature indicate that there is a need for ongoing research into the educational needs and curricula for nurses who practice palliative care in homes in Africa, and this study may act in some way to address this need.

3.3.1 Palliative care curriculum and home care

Regarding palliative care curriculum for caregivers who care for patients at home, American literature notes that although there are increasing numbers of persons and their families who need to be cared for in a non-hospital setting, such as their own home, education for this type of care has not kept up with the increasing need (Frommelt, 2003). A gap in literature and a consequent need to carry out ongoing study for curricula for nurses who provide home care is thus identified in the USA. As I explain in the following chapter, the situation is similar in South Africa as increasing numbers of patients who require palliative care are being cared for at home.

The APCA notes that home-based palliative care is required in Africa; however it acknowledges that there is a lack of evidence to guide this issue:

Since the beginning of the HIV/AIDS epidemic, home-based care (HBC) has been promoted across Africa and elsewhere in the world as a suitable model for delivering services to people living with HIV and AIDS (PLWHA) and their families. However, not much evaluation has been done to establish what constitutes HBC or how palliative care can be integrated into these services... There is general assumption that HBC is the most feasible model for integration of palliative care into existing services for PLWHA, although this view is supported by a limited evidence base. (APCA, 2004, p. 12)

The above quotation points to a lack of research in home-based palliative care in general, and may be extrapolated to point towards a lack of research in curriculum for home-based palliative care in Africa.

3.4 A curriculum of palliative care: Benefits and challenges

Curriculum and education for nurses who care for the dying has been reported to be useful for some aspects, and criticized as generally inadequate for other; Frommelt (2003, p. 15) noted positive aspects of education in that student nurses who participated in a structured educational programme on death and dying had a more positive attitude towards caring for terminally ill patients and their families than those who did not participate. Student nurses were found to have a significant improvement in their level of comfort towards the subject after participating in the programme. They stated that they felt that discussion around the personal experiences of the instructor in caring for the dying was of benefit to them, as was discussing “true-life” situations.

Some perceive that current palliative care curricula are generally not adequate in meeting all the needs of learners, and Wittenberg-Lyles *et al.* (2007) note that although palliative care, and specifically end-of-life curricula, have increased in number and quality over the past few years, the trend in structure has been to emphasize knowledge acquisition and skills rather than focusing on caregivers’ attitudes.

Lloyd-Williams and MacLeod (2004) also discuss “attitudes” and note that in general, palliative curricula are inadequate as they emphasize knowledge and skills and pay little attention to personal attitudes (what kind of doctor or nurse the healthcare provider ought to be). They refer to knowledge and skills as “professional content” and personal attitudes of caring as “professional process”.

While the knowledge and skills of palliative medicine are well defined, there are elements of the medical care of people at the end of life that are more difficult to outline; the way in which doctors learn to care and indeed should care has not been clearly delineated. (Lloyd-Williams & MacLeod, 2004, p. 685)

In the following paragraphs I link discussions around knowledge, skills and attitudes in palliative curriculum to three theories of curriculum: technical, practical and emancipatory. I also look at autobiography and biography as curriculum theories. The first three types of curriculum resonate with Habermas’ theory of knowledge, as Habermas identified three basic cognitive interests: technical, practical and emancipatory (1972). I expand on these three ways of knowing in Part Three. In general curriculum theories can be distinguished on the basis of differences about the nature of reality (ontology), the nature of knowledge (epistemology) and the nature of enquiry methods (methodology).

3.4.1 Curriculum theory as technical, objective and predictable

Curriculum theory identifies a type of curriculum referred to as “technical” or “empirical-analytic.” Such a curriculum can be understood in terms of reality as an ordered set of interlocking systems which operate according to predictable patterns or universal laws. A technical curriculum objectively does not consider context and can be viewed as consisting of a number of variables which are analytically separate parts of an interacting system. A variable can be manipulated or controlled in order to achieve a predicated and certain outcome. The variable is clearly defined and it is assumed that there will be a predictable outcome if this variable is manipulated. For example, in palliative care a variable may be “pain”. A technical curriculum would consider the type of pain and discuss medication and interventions required to control that pain.

The technical curriculum assumes that if analgesia is given then “physical pain” will be controlled and we can be certain that an outcome, such as reduction in pain, will occur. This is the dominant theory in the field of curriculum (Cronbleth, 1990). This dominance arises out of the influence which the ontology of science has exerted over many fields - curriculum being one of them (Frame, 2003).

Ury, Arnold and Tulskey (2002) in an American context discuss palliative care curriculum development as a content and process-based approach and advocate that development of a palliative care curriculum be divided into four phases: a needs assessment, curricula design and defining of objectives, implementation and evaluation. Their discussion places palliative care curriculum within a technical framework as it assumes that meeting pre-identified objectives will lead to predictable outcomes.

A technical type of curriculum, with pre-identified aims and objectives, is reflected in European palliative care: in 1997 the European Association for Palliative Care (EAPC) proposed that minimal recommendations and standardized outcomes for palliative care training and evaluation for both doctors and nurses be identified (de Vlieger *et al.*, 2004, p. 402). The EAPC has tried to unify the European voice of palliative care education through its initiative ‘One Voice, One Vision’. Finding one voice, one vision and corresponding aims and objectives of palliative care may prove to be elusive, since defining aims within a palliative care curriculum may be difficult. For example, if we say that an aim of a palliative care curriculum is that students know about and accept importance of personal, psychological, existential and spiritual issues at the end of life (Just, Schult, Bongartz & Schnell, 2010), it may not be entirely clear what we mean by “know about” or “personal”, and so on. Clarification of these terms may mean that the aims may become complicated, and the list of aims may grow like a weed, become tangled, unwieldy and not be of much use. Even long lists do not say anything about the reach of any attainment; does the student know about these things or not?

An “aims-and-objectives” technical curriculum assumes that there can be a commonality and consensus among curriculum planners about the objectives of a curriculum and that the objectives can be translated into predictable outcomes, aims or practice. A technical, rational curriculum promotes ontology of knowledge as propositional and theoretically based, and theory and practice are perceived dualistically: theory developed through research and practice can be linked to the application of research findings by practitioners.

This situation may apply in some situations; for example, a theory around an operation to remove a brain tumour may be tested out in a laboratory using animals, such as mice. The theory can then be translated to practice, as what works in a laboratory will usually work in practice. However, aspects of palliative care, such as spiritual care, cannot be tested out in a laboratory before being applied in practice.

3.4.2 Curriculum theory as practical, subjective and unpredictable

In contrast to theoretical views of the technical curriculum, Eisner (1967) believes educational objectives which are clearly and specifically pre-identified can hamper as well as help the ends of instruction. He advocates that an unexamined belief in pre-identified objectives within a curriculum can easily become a dogma which may in fact hinder the very functions the curriculum was originally designed to serve. Eisner places a focus of curriculum and educational endeavour on the growth of the learners and advocates personal growth, respect for others and a joy of learning. The focus in a practical curriculum is on epistemology or ways of knowing about something.

In contrast to the technical curriculum where there is a focus on objectivity and predictability, the practical curriculum assumes there to be more to a curriculum than simply reaching a predetermined aim. The practical curriculum invites subjectivity and assumes that knowledge is produced through a process involving human judgement and the development of consensual meanings. The practical curriculum considers context and assumes that behaviour cannot always be predictable. This practical theory of curriculum can equate to what Wittenberg-Lyles, Greene and Sanchez-Reilly (2007) and Lloyd-Williams and MacLeod (2004) refer to as a curriculum to develop “personal attitude”: there is more to a curriculum than just learning knowledge and skills around caring. The practical curriculum involves reflection and deliberation and aims to make a learner able to make “sound judgments” (Frame, 2003, p. 24). Whereas knowledge and skills are central to the technical interest, judgement is central to the practical interest (Grundy, 1987). A practical curriculum focuses on classroom interaction and produces opportunities for learning, rather than on predetermined outcomes.

By way of explanation, a technical curriculum will assume that if a patient has pain, then treating the physical pain with medication will improve the pain. A practical curriculum will aim to look at “pain” as a broader concept, such as “suffering beyond pain”. Suffering implies more than physical problems. Understanding and relieving suffering would necessitate a deep engagement between the patient, family and healthcare provider. One could not assume that changing one variable, such as analgesia, would lead to an improvement in suffering. Suffering beyond pain is particularly pertinent to consider in curriculum in an African context; for example, patients may be unable to access analgesia because they cannot reach a hospital to obtain medication.

Schwab (1969), working in a practical curriculum, noted that the concept of curriculum should be understood as involving what he referred to as four common places: teachers, learners, subject matter and milieu. This echoes Stenhouse (1975), who produced what is known as a “process model” of curriculum theory and practice. He defined curriculum tentatively as an attempt to communicate essential principles and features of an educational proposal into practice. It follows from this that practical curriculum inquiry and development must be context-specific and capable of effective transmission into practice.

Wittenberg-Lyles *et al.* (2007) and Lloyd-Williams & MacLeod (2004), working in a Northern context, seem to advocate that palliative care curriculum becomes more practical as they see a need to enhance “personal attitudes” which they feel are relatively neglected with the technical curriculums’ emphasis on knowledge, skills, aims and objectives. However, in contrast to their views, Olthuis and Dekkers (2003) argue that palliative care curriculum differs from other forms of medical curriculum because it specifically focuses on personal attitude:

Palliative care training can correct this imbalance between knowledge, skills and attitudes. In our view incorporating palliative care into medical training not only improves the quality of care, but also contributes to the moral attitude of the doctors being trained ... Moral attitude focuses on the capacity to respond to others in a humane manner that can be compared to the way a virtuous doctor acts (Olthuis & Dekkers, 2003, p. 928).

There are differing views on existing palliative care curriculum. Some believe it to be too technical and advocate that it becomes more practical. Others advocate that it is already practical, and should be expanded in other areas of medical training such as developing a moral, caring doctor who has empathy with her patients. There is uncertainty around what a palliative care curriculum is or should be, and such issues may be of particular importance when developing an African palliative care curriculum, since I show in Chapter Five that a curriculum can have a profound effect on continuing or hiding marginalization and oppression.

3.4.3 Curriculum theory as oppressive and emancipatory

Curriculum theory proposes that any curriculum forms a contested space, a site of struggle over what constitutes the truth, the valuable and the reasonable, as well as conflict over who is entitled to be counted as worthy of access to it (Ayers, Quinn & Stovall, 2009). Some scholars regard a curriculum as being able to play some role in increasing awareness of injustices in society and increasing ability of learners to transform society. Apple (1982) believes that schools and associated curriculum are but one of many products of powerful interests and forces, and practices and performances of schooling are causeways for the flow of power as regulated by authorities. An emancipatory curriculum theory encourages individuals to reflect on a current situation and to realize whether it needs modification. Bernstein (1976) believes that a curriculum can determine what counts as valid knowledge, pedagogy and evaluation of knowledge.

Following this vein of thought, a curriculum (such as a curriculum for palliative care) could potentially legitimize and reproduce canonical divisions of knowledge, reflecting and reproducing the relative power and privileges of those communities with investments in particular health sciences. For example, a university curriculum which prioritizes use of a specific type of drug which was developed by a Professor at that university may imply that this drug is of more importance than other similar drugs, and this may happen in both a North and South context. A palliative care curriculum may be uniquely placed to disrupt canonical divisions of knowledge.

Let me expand on this idea, as I show that a palliative care curriculum can act in an emancipatory role. Hafferty and Franks (1994) discuss a distinction between a formal, informal, and a hidden curriculum in medicine. While the formal curriculum comprises course work, laboratories and clinical clerkships, the informal curriculum exists on an interpersonal level. Students learn informally from those they work with every day, whose behaviours and philosophies they emulate. The hidden curriculum exists on an institutional level where, for example, students learn the norms of a hospital culture.

Fins *et al.* (2003) discuss a formal and a hidden curriculum and promote that training in palliative care can act as a means for learners to counteract an informal or hidden curriculum which may be promoting one way of thinking at the expense of others. They introduced a curriculum where students reflected on their practice and specifically reviewed *humanistic dimensions of practice* (Fins *et al.*, 2003, p. 308).

They proposed that humanistic care is often displaced by a hidden curriculum which promotes a need to master diagnostic and therapeutic skills, and the impacts of a hospital culture may be at odds with end-of-life care education. Spending time with patients or time to reflect on psychosocial or family dynamics is often not prized, and students and trainees report feelings of conflict between their own sense of morality and the work that is expected of them. Under the influence of a hidden curriculum students experience a reversal of gains in areas of humanistic skills, communication abilities, tolerance to diversity, and attention to patient and family responses to illness. Fins and Nilson (2000) advocate that palliative care training, by exposing a hidden curriculum, can act to reverse the effect of the hidden curriculum. However this discussion may be viewed as assuming that students are unable to “think out of the box”, are not autonomous, and cannot adapt to situations where humanistic skills and communication abilities are needed.

Literature on curriculum as potentially oppressive or emancipatory in home-based palliative care seems to be largely invisible. In providing a rationale for this study I presented a scenario where a nurse felt unable to assist a child and her grandmother at home, and this raises some issues around oppression and emancipation: the nurse could be regarded as being oppressed because she felt futile, and the child could be viewed as oppressed because she was denied access to a doctor. If such issues were not addressed in a curriculum then the curriculum could be regarded as oppressive since it does not consider palliative care in context.

3.4.4 Curriculum theory as autobiography and biography

Curriculum has been looked at in many ways and curriculum scholars have highlighted that a curriculum should consider the lives of the teacher and student outside the classroom. Some curriculum theorists are of the view that curriculum should not be developed or offered in a vacuum of life experiences, and that curriculum is not immutable. The focus in autobiography and biography is on “methodology of knowledge” – what methods do we employ to know about something. Connelly and Clandinin (1988) advocate that there is no better way to study curriculum than to study ourselves, and many have written around understanding a curriculum as autobiographical or biographical text:

The effort to understand curriculum as autobiographical and biographical text emerged in the 1970s as an alternative to the conceptual-empirical and quantitative social science research dominating education at the time.

(Pinar, Reynolds, Slattery & Tauban, 2002, p. 564)

Ivor Goodson, a British curriculum scholar who has worked in many countries, is particularly concerned with how a curriculum and, specifically subjects like biology, geography and vocational training, relates to the reproduction of class inequalities. He promotes that “*we need to know more about teachers’ lives*” (Goodson, 1989, p. 138). In teaching and in learning he proposes that we should look beyond a written curriculum with predetermined objectives, and advocates that we look beyond the classroom and at issues such as life-history as a source and method for the study of schooling. In life-history Goodson saw:

A dynamic model of how syllabuses, pedagogy, finance, resources, selection, the economy, and the like all interrelate (Goodson, 1989, p. 76)

Taking cognizance of the work of Goodson and other curriculum theorists, I see a need to look at a curriculum beyond the confines of a classroom or a lecture theatre. In this study I transpose curriculum theorists’ views to caregivers in that I use a form of biography to report on the experiences of caregivers who practice palliative care at home.

In Chapter Six I present how I gathered data from caregivers; I consider that the data collection method allowed them to tell their own stories about their experiences when caring for patients at home, and I think of their stories as “palliative care autobiography”.

3.5 Conclusion

In this chapter I introduced the reader to a landscape of curriculum and revealed that curriculum is more complex than just a written syllabus to describe what topics need to be covered in a period of time. In providing an overview of curriculum definitions which place curriculum as either a narrow or broad concept, the reader could glean information around the multi-faceted and finely nuanced potential of a curriculum. In this study I work with curriculum as a complicated, broad idea and I focused on palliative care curriculum, discussed the role of nurses in palliative care and the development of palliative care curriculum for nurses in the North. There is notably little literature on curriculum for palliative care in the South, and in particular for home-based palliative care. I outlined benefits and challenges of palliative care; benefits included caregivers adopting a positive attitude toward their patients who faced the end of their lives. Challenges identified by some authors point towards palliative curricula which tend to focus on knowledge and skills acquisition with relative neglect of development of the caregiver as a morally caring person.

I provided an introduction to four differing curriculum theories and noted that a technical palliative care curriculum focuses on knowledge acquisition and technical skills with relative neglect of subjective experiences such as “personal attitudes.” A technical palliative care curriculum will be based on the premise that science solves most societal problems. Technical rationalism promotes ontology of knowledge as theoretically based and theory and practice are perceived dualistically: theory is developed through research and practice is linked to the application of research findings by practitioners.

In a practical type of curriculum, some are of the view that there is more to a curriculum than simply meeting preordained objectives and any curriculum should take context into account. Some are of an opinion that palliative care curriculum does not consider how to develop a “good” doctor or nurse. Others believe that palliative care curriculum is uniquely placed because it does consider issues beyond how to meet pre-identified objectives, such as how to develop a moral, caring health professional.

In a critical stance, some curriculum theorists are of the view that a curriculum can act to entrench social injustice or alternatively advocate for societal transformation and uplift the marginalized. A palliative care curriculum could act to entrench social injustice or to counteract social injustice by, for example, exposing a hidden curriculum.

Biographical or autobiographical curricula consider the person within their own context, and I see a need to look at a curriculum beyond the confines of a classroom or lecture hall. The study explores a curriculum as a preactive knowledge source and uses the biographical experiences of caregivers who practice palliative care as an interactive curriculum.

This study aims to set a precedent for home-based palliative care curriculum as there is little literature available on palliative care curriculum for caregivers who work in rural patients' homes. In the following chapter I introduce the reader to the landscape of rural homes within the context of this study.

CHAPTER FOUR

The landscape of rural homes

4.1 Introduction

In this brief chapter I aim to deepen the reader's awareness of context and specifically aim to increase awareness of healthcare in rural homes in the context of the study. I highlight that the Northern context in which palliative care emerged and the Southern context in which palliative care gets practised in rural homes are vastly different. In particular, I emphasize that home care is more necessary in the South and I review the following: who cares for patients, who needs caring at home and how people access home care. The WHO (2002) describes home care as:

Home care is any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of community home-based care is to provide hope through high-quality and appropriate care, that helps ill people and families to maintain their independence, and achieve the best possible quality of life (WHO, 2002, p. 8).

Home care is a recognized way of caring and its definition portrays it as a broad type of care with many aims.

4.2 Who provides care at home?

In South Africa, within a home care context patients at home are largely cared for by professional caregivers, such as a nurse, or by non-professional caregivers. Non-professional caregivers are community members who enter the homes of the sick to provide care, and have been referred to by a variety of names: HBC workers, community health workers and community care givers (Wringe, Cataldo, Stevenson & Fakoya, 2010). In this study I refer to informal healthcare workers as HBC workers.

Their training is not standardized nor accredited as there is no national curriculum or accrediting body for HBC workers, and so HBC workers do not work within the framework of a curriculum. In South Africa since 1998 a rapid growth in programme activities and budgetary allocations for a comprehensive approach to HIV/AIDS has been responsible for the emergence of a large HBC worker infrastructure (Schneider, Hlope & van Rensburg, 2008). Several “models” are used to deliver palliative care within home care in Africa, and a review of models is available in a preliminary report from the APCA (2004). A model of home-based palliative care delivery known as the integrated community-based home care is used by hospices in South Africa to link home care and palliative care (Defilippi 2005). In this model a variable number of HBC workers are supported by a nurse.

If we review the numbers of people available to care for the ill in a Southern arena, we see that there are fewer nurses and doctors available to care than, for example, in the USA or UK (Table 2).

Country	Nurses per 1000 people	Doctors per 1000 people
Vietnam	0.53	0.56
India	0.6	0.8
South Africa	4.08	0.77
USA	9.37	2.56
Australia	9.71	2.47
UK	12.12	2.30

Table 2: Nurses and doctors per 1000 people in various countries
(WHO, 2007)

The shortage of healthcare workers is an international phenomenon (Dal Poz *et al.*, 2006). The sources quoting a nursing shortage in South Africa are abundant and varied (McGrath & McGrath, 2004). A study in 2007 revealed that 42% of professional nurse posts in KwaZulu-Natal were unfilled (South African Department of Health (DoH), 2004). The South African DoH in 2004 noted that rural areas are more affected by nurse shortages than urban areas.

These statistics do not speak of an urban: rural divide in healthcare resources and do not speak of the suffering faced by patients or the challenges faced by caregivers. The statistics tell of the relatively few nurses and doctors available to assist those who have a life-limiting illness, but do not tell us where these health professionals work - although an assumption can be made that there are fewer health professionals available to care in rural homes in the South when compared to the North.

4.3 The home as a necessary place of care

In the South, the home has evolved as a very necessary place for care as many people need to be cared for in their own homes. People who live in rural, isolated areas have little access to a hospital or clinic as these healthcare facilities can be far from rural homesteads and transport can be erratic and expensive. Home care may be only type of care available. Specifically in South Africa, people who have HIV and AIDS require caring for at home and literature notes that the home as a place of care has evolved in response to the HIV and AIDS epidemic (Schneider *et al.*, 2008, p. 182). Uys and Cameron (2003) note that many deaths related to AIDS take place at home. Studies have shown that the majority of people in developing countries will die in their homes under the care of their family or neighbours (Clemens *et al.*, 2007, p. 174).

In the North the home may not be as necessary as a place of care. People have more choice around where caring occurs and may be cared for in various places including hospitals, hospices or at home. The common place of care, especially when dying, is a hospital. In the UK, for example, most deaths occur in a hospital and do so following a period of chronic illness, such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most people wish to be cared for and to die in their home, but the number of people who are able to do so varies with age, geographical area and, most significantly, medical condition (National Audit Office, 2008).

4.4 How do people access home care?

In South Africa there is a shortage of doctors and the healthcare system, particularly in rural areas and clinic-based nurses would refer patients to a hospital for advice.

Some patients are referred to HBC organizations by hospital-based healthcare providers (Campbell, 2004). However, both literature and my experience reveal that most patients will access home care through self-referral to an HBC worker or a home-based nurse, since in Africa in general there are weak referral system links between HBC organizations and the public health sector (Mohammed & Gikonyo, 2005). Thus a patient could access home-based palliative care without any input from a hospital-based nurse or doctor. This situation has potential challenges, as I explained earlier, and information from a hospital regarding diagnosis and prognosis may be difficult to obtain. A situation could arise where a home-based caregiver becomes unsure of what is causing the patient's problem, and thus the caregiver must act in a situation of uncertainty due to lack of clinical information about a patient's disease or condition.

4.5 Conclusion

This short chapter aimed to illustrate challenges in home-based palliative care in the South which may be specific to the South. For example, in the South there are fewer nurses and doctors available to offer care, including home-based palliative care, for patients. In the South the home becomes a very necessary place for care, as healthcare facilities may be far from patients' homes and transport to healthcare facilities may be erratic and expensive. In the North home care may not be as necessary as people have more choices around place of care, and literature indicates that people are cared for and die mostly in hospitals or hospices.

Referral systems between a hospital and an HBC organization may not be ideal, and a patient may self-refer to an HBC organization. There is the potential that a patient accessing palliative care at home in the South may experience no involvement from a hospital-based nurse or doctor, and the only person reviewing the patient may be an informal caregiver supported by a nurse. This opens a space of uncertainty for the caregiver, as she may not know whether she is caring for a patient who is expected to live or to die. This has important implications for the type of care which the patient should receive.

Part Two of the study has provided the reader with foundations for the study. Palliative care emerged in the North as a response to prevalent norms and practices around illness, dying and death. Palliative care has been introduced from a highly developed context to one that is substantially different - rural homes in Africa. I indicated that although home care is very necessary in the context of this study, there may be challenges in providing home care including home-based palliative care.

I discussed the fact that curriculum is complex, can become a contested space and can have powerful effects on students. A palliative care curriculum in the context of this study can be of considerable importance as it is introduced to a situation where there may be little existing knowledge around an idea of palliative care, and a curriculum can act as a very potent and important knowledge source. There are gaps in literature around home-based palliative care and the APCA has called for research in this area. Research which considers the experiences of caregivers who practice home-based palliative care may provide insights for African palliative care curriculum designers.

Qualitative research which employs autobiographical methods may provide caregivers with an important voice in their own context of care.

In the following chapter I provide an overview of research methods I used to enable me to look at a nurses' curriculum for palliative care and the experiences of those who have been trained using this curriculum.

PART THREE:

A PARADIGMATIC AND METHODOLOGICAL FORAY

Part three comprises two chapters and provides an overview of paradigms and methods used for data production. In the first of these chapters I provide an overview of the paradigmatic orientation of the study and this orientation is important as it forms the basis for my decisions around data collection and data analysis. A paradigm strongly influences how we look at things in the world.

In the second chapter I introduce the reader to the study participants and study site. I provide information on decisions around my choice of a visual methodology and as the methodology is new in this context, I illustrate some of the benefits and challenges surrounding it. I expand on rigor in qualitative research methods.

CHAPTER FIVE

A paradigmatic foray

5.1 Introduction

In Part One, Chapter One I introduced the reader to paradigms and discussed that health science generally operates within a positivist paradigm where paradigms are taken for granted and are objective, rational and detached. In this chapter I expand on paradigms which I use throughout the study, and I present the paradigmatic orientation of this study. Such an overview is required as the choice of data collection methods and decision around analyses of data are underpinned by the paradigm of the study. The paradigms I review are positivist, interpretative, critical and post-structural. I see paradigms simply as differing ways of looking at things.

5.2 A positivist paradigm

Within a positivist paradigm a researcher will gather information about facts in an objective and detached manner (Terre Blanche, Durrheim & Painter, 2008). They often make use of quantitative methods and are concerned with issues such as validity, generalizability and reliability. Positivism generally equates to ontology of science and the researcher believes that what is to be studied consists of a stable, external reality. Examples of methods used in positivist research are case-control study and randomized placebo control study. Positivists believe that there is a “truth” that lies out there and is waiting to be discovered (Giroux, 1981). For example, a positivist researcher would ask - does Tenofovir (a drug used for HIV disease) prevent HIV transmission from one person to another - yes or no? With regard to palliative care research, the positivist would ask does the curriculum prepare a nurse for palliative care practice – yes or no? Reality is external, fixed¹⁹ and objective.

¹⁹Fixed - an adjective that means one of three things: fastened, attached, or placed so as to be firm and not readily movable; firmly implanted; stationary; rigid.

The promise of positivism was that scientific disciplines which modeled themselves on this paradigm would achieve “true scientific status”. To be scientific means to be able to formulate true, certain, universal, law-like statements that provide causal explanations of the world.

5.3 An interpretative paradigm

In an interpretative paradigm a researcher believes that there is no absolute single truth out there waiting to be discovered. The interpretative paradigm assumes that the nature of social reality involves agreement among humans about what constitutes reality, and believes that reality can mean differing things to differing people. This paradigm prioritizes epistemology which considers issues such as what is knowledge, how is knowledge acquired, and how do we know what we know? Knowledge is not seen to be free of the interests, beliefs and values of the human agents who create it (Frame, 2003, p. 24). The interpretative researcher will consider people’s subjective experiences of their world; their internal reality. An interpretive researcher will employ methods such as interviewing or participant observation as they rely on a subjective relationship between a researcher and participant. They aim to explain a reason behind a societal action. For example, an interpretative researcher would ask why do some teenagers choose not to use Tenofovir as an HIV prevention measure? They may conclude that some teenagers believe that Tenofovir may make them infertile and therefore choose not to use it. With regard to palliative care, researchers may ask what does the term “spiritual” as used in palliative care curriculum mean to you, and why does it mean this?

5.4 A critical paradigm

The critical paradigm considers overtly political research, and the researcher believes that research should be carried out mainly to improve the conditions of all humans. Critical researchers, like interpretative researchers, believe that knowledge is socially constructed and that research should be situated in broader social, political and economic contexts (Frame, 2003, p. 27). Researchers would consider how contexts influence knowledge availability; for example, is it prohibitively expensive for young children to attend school?

A critical paradigm would ask questions around issues in the North compared with the South - for example, why does research around drugs for HIV occur in the South when such drugs are only available in the North? Researchers believe that reality can be manufactured and manipulated for gain.

Another example: a critical researcher would ask why teenagers think that Tenofovir causes infertility. They may find that one teenager has misunderstood a magazine article about the drug - because his reading skills are poor. His reading skills are poor because he has been educated under the system of apartheid, where the reading skills of African students were neglected. The critical researcher may work with the teenagers and together they may realize that reading skills are poor and take action to improve reading skills.

From a critical stance the world is a creation by the powerful and the privileged, and the world is manipulated to sustain power and privilege (Chavez, 2006). A fundamental assumption is that knowledge is contestable and contested at the level of values, beliefs and interests which are all intertwined. The critical paradigm begins with an assumption that existing knowledge is contestable and the paradigm means engaging in political processes which are influenced by the historical and social context in which they take place. The critical researcher aims at transformation and uplifting the marginalized.

Within a critical stance, the interests which may be served by palliative care and its curriculum need to be explored and need to be made transparent. The critical researcher may ask the following: does palliative care curriculum appropriately address all the needs of patients? If not, why not? What can be done to improve the situation?

5.5 A post-structural paradigm

The post-structuralist researcher is inherently connected to views of humans as different to other life forms due to the use of language as a means to represent reality. Lyotard (1993) claims that the “self” (or a person’s reality) is structured and defined in a context of language. A post-structuralist researcher is interested in discourse and the word ‘discourse’ can mean differing things to different people.

Phillips and Jørgensen (2006, p. 1) describe discourse as follows:

..underlying the word discourse is the general idea that languages are structured according to different patterns that peoples utterances follow when they take part in different domains of social life, familiar examples being ‘medical discourse’ and ‘political discourse’.

Discourse can be viewed as a particular way of talking about and understanding our world. Whether we are aware of it or not, our ways of talking are not neutral reflections of the world. Taking this idea forward, our ways of talking (discourse) have potential to create oppressive conditions or to change oppressive conditions. As an example of this thinking around discourse consider the following story:

Thabisile, a Zulu artist, has cancer. She has exhibited many of her paintings at prestigious galleries and her vivid, colourful paintings depict her experiences of the cancer. She has many friends, has a busy social life and loves art. She is involved with teaching an array of art students.

She visits a doctor looking a bit dishevelled and says “I am suffering. I can’t paint any longer. My world is darkened. My canvas is empty and I have nothing left to teach. I have pain today. It hurts. It is in my stomach writhing about like a snake. Don’t give me any morphine.²⁰ I tried that before and it made me sick. I find that dagga²¹ helps my nausea and helps me cope with my dejected, blackened, colourless life.”

The doctor writes in his records: “Patient: 55 year old black female. Unmarried. Cancer of the stomach. Stabbing pain, left upper quadrant of abdomen. Refuses morphine. Using illicit substances? Depressed - refer to psychologist. Refer for spiritual counselling as cancer aggressive.”

Thabisile has described that she suffers, and Pastrana *et al.* (2008, p. 224) have described that a common theme in palliative care discourse is an intention to relieve a patient’s suffering. If we apply the WHO definition of palliative care, then we consider only physical, psychological and spiritual aspects of suffering (as the doctor does in the story above). Other aspects of suffering, such as artistic/creative suffering, are not included in general palliative care discourse, and yet this type of suffering is utmost for Thabilisile.

²⁰ Morphine is a drug used for pain control.

²¹ Dagga is the dried leaves and flowers of the plant *Cannabis Sativa*.

In his medical records the doctor has used a “WHO palliative care discourse” in which he considers physical care, psychosocial care and spiritual care. The post-structuralist would point out that this is reductionist and does not cover all types of suffering which may be experienced. Our discourse, as palliative caregivers, may discriminate against or not act to acknowledge Thabisile’s idiosyncratic ways of suffering. Thus the “WHO palliative care discourse” does not represent a “neutral” reflection of the world.

A discourse causes a reduction of possibilities, and all possibilities that a discourse excludes are termed by Laclau and Mouffe as “the field of discursivity” (Laclau & Mouffe, 1985, p. 111). For example, the “WHO palliative care discourse” excludes other types of care, such as care for an artist’s creative potential. The field of discursivity is understood as everything outside a discourse, but because a discourse is constituted in relation to an outside, it is always in danger of being undermined by things which are on the outside. The post-structuralist would pay attention to what types of care are not included in palliative care discourse. It would point out that there are perhaps tangential discourses, such as Thabisile’s problems around not being able to be creative. Other tangential discourses which seem excluded by the “WHO palliative care discourse” may include issues around education (a sick child may have specific educational needs) and legal issues (a sick patient may wish to draw up a will).

My previous discussion around a death-denial discourse has indicated that discourse around dying is not surrounded by a total societal consensus, and thus palliative care discourse is not “neutral”. O’Connor and Payne (2006) propose that discourse analysis has the potential to contribute to new ways of seeing palliative care practices through deconstruction of meanings, and advocate that discourse analysis may be useful when exploring how different versions of reality are produced, negotiated and evoked in conversations and in texts. They also believe that a disadvantage of discourse analysis is that because the analysis is focused on language and uses text and talk, the approach may be too remote from clinical practice, *“It may be difficult to infer issues around how to change behaviours because, arguably texts merely describe exiting phenomena rather than offer transformative possibilities”* (O’Connor & Payne, 2006, p. 833).

As I explain later, I take this into account when considering methods to use in this study, as discussions around palliative care in training or in healthcare facilities may be far removed from palliative care practice in rural homes.

5.6 Paradigmatic orientation in this study

The paradigmatic research orientation of this study can best be described as critical paradigm with a post-structural slant. Let me expand on what I mean.

Working within a critical paradigm, I note that a concept of palliative care is developed in the North and lies largely within the realm of health science. The idea of palliative care may not have a universal quality, but may be the result of conventions generated through countless decisions of people living in societies, and transposing palliative care curriculum and practice from the North to the South may reflect a hegemonic flow of knowledge and ideas. Hegemonic flow of ideas is found in other spaces, for example ideas around hygiene:

Hygiene, often a sensitive topic in the Western Hemisphere,

is something Africans are thought to lack. This is false...

If most of "us" do not follow the Western way of life

– the use of body perfumes and deodorants- it does not

indicate that every African is filthy. Body aroma, many

Africans would agree, is a way of identifying individuals

without seeing them. This can be useful (Sodimu, 2006, p. 1).

In particular, in South Africa there is ongoing discussion and debate in a critical paradigm around any curriculum. During the apartheid era curricula for schools and for healthcare were determined exclusively by whites. People classified as “non-Whites”²² were marginalized. The authoritarian nature of the State ensured that decision making in curriculum was undertaken along racial and bureaucratic lines. In practice, this meant that curriculum development was in the form of a syllabus developed by four white-only provincial education departments.

²² Apartheid refers to a racial segregation policy of the Government of South Africa from 1948 to 1994. Under the apartheid system, “non-whites” – classified as Bantu (black), coloured (mixed), or Indian – did not share full rights of citizenship with the white minority. For example, black people could not vote in parliamentary elections, and until 1990 many public facilities and institutions were restricted to the use of one race only. President F. W. de Klerk repealed the key elements of apartheid legislation and by 1994 apartheid had ceased to exist.

Departments of Education established for “non-white citizens” could enhance the local relevance by adding to the core curriculum, but were not permitted to remove anything (Graham-Jolly, 2003, p. 3). A curriculum in education was complicit in engraining apartheid ideology. Following the demise of apartheid there is an expectation that teachers will help rebuild national culture and identities (Hargreaves, 1998). Apartheid permeated, distorted and corrupted all healthcare sectors, including healthcare professionals’ education (Baldwin-Ragaven & London, 1999). The training of healthcare professionals within an apartheid context did not focus on the building of healthcare systems based on human dignity. The practice of institutionalized racism and subjugation within training institutions was complicit with apartheid theory. Healthcare training separated social, political and economic issues from healthcare issues. For example, poverty and diseases of poverty were commonly mentioned in health science curriculum but within a context that only focused on the signs of disease and corresponding curative interventions. In healthcare curriculum poverty and segregation became normalized, and if only focusing on disease issues with relative neglect of broader social issues, a palliative care curriculum may in some way also act to normalize poverty.

Some theorists consider that oppression and marginalization can be products of language (Bourdieu, 2001). An overall idea of Laclau and Mouffe (1985) discourse theory has at its starting-point that discourse constructs the social world in meaning, and that owing to the fundamental instability of language, meaning can never be permanently fixed or total. As an example, consider pain which cannot be described in terms of pain, since a patient cannot stick a needle into a doctor’s arm to describe that his pain feels like a needle-prick. Understanding the pain of another person relies on their use of language, an understanding of their language and a degree of empathy. The meaning of pain is unstable and cannot be permanently fixed. A discourse around pain may cause a reduction of possibilities in ability to describe or understand pain, but this does not mean that pain does not exist and that attempts should not be made to describe and understand it.

The field of discursivity is understood as everything outside a discourse, and the post-structuralist would pay attention to what types of care are not included in palliative care discourse. If meaning is fluid and malleable, then it may not be possible to ultimately fix a meaning, and a way may be opened for constant social struggles about meanings, definitions of society and identity, with resultant social effect (Phillips & Jørgensen, 2006, p. 24). The creation of a meaning centres on a society fixing that meaning. Literature advocates that we carefully consider the use of language in describing and defining palliative care:

While many may feel we focus unduly on semantics, we believe
that the terminology used does have implications for how we
conceptualize, organize and provide care (Tishelman, 2007, p. 4).

Taking cognizance of the view of Tishelman (2007) that language is important, I stress that this study does not carry out a study of language used in a curriculum or language used by caregivers, and the study does not form a discourse analysis. Rather, taking cognizance of the work of O'Connor and Payne (2006), who caution that discourse analysis is removed from practice, I aim to juxtapose text from a curriculum with a practice. At one level rural home-based palliative caregivers have 'personal discourses' around caring which may reflect their personal memories, knowledge and opinions as well as those shared with other caregivers and other members of their community. At another level they have knowledge of a 'palliative care discourse' which they have experienced through a written text such as a palliative care curriculum. Such palliative care discourse may represent shared social fixing of meanings which are fixed by others who do not provide palliative care within rural homes and as such caregivers may face negotiations and mediation between curriculum and practice.

A key term in discourse theory is "discursive struggle", and this proposes that different discourses, as representing different ways of talking about and understanding the social world, are engaged in a constant struggle with each other to achieve hegemony (Laclau, 1998, p. 154). A post-structuralist slant would view whether palliative care discourse may reflect fixing a meaning that reflects hegemony of ideas, and all hegemonies must be endlessly interrogated.

In this study I analyse the experiences of rural caregivers (nurses and HBC workers) around their experiences when practicing palliative care to fathom their “personal discourse”, and I explore a text for a palliative care curriculum to represent a broader “palliative care discourse”.

Palliative care curriculum developers in the North may be clear around how palliative care is conceptualized by healthcare professionals, patients and families, and hence the curriculum may become certain around notions of palliative care. Curriculum developers may be clear about what palliative care needs to achieve and how it will be received and valued. Curriculum developers in a context of African rural homes may be less sure, as the discourse of palliative care in a curriculum has been transposed in an unmodified way. The curriculum which was certain in one context may become uncertain in another. I concur with Mouton and Muller (1997) that exploring texts, such as curriculum, is important

5.7 Conclusion

The aim of this chapter was to introduce the reader to research paradigms used in this study, and I wished to highlight a particular type of thinking that underpins each paradigm. The promise of positivists was that science would be able to formulate true and universal explanations of the world. Contrary to the claims of positivists, some believe that science is never value-free and any research or theorizing has moral and political dimensions. In an interpretive paradigm the researcher is concerned about the individual and a central endeavour is to understand the world of subjective experience.

The basic premise of critical theory is that human beings are always subject to ideological distortions. I make an assumption that a critical view is of particular relevance in post-apartheid South Africa, where health care professionals and educators were complicit in oppressing the marginalized during the apartheid regime. My particular framing, which will be deployed in this study, is that palliative care curriculum may represent a flow of hegemonic ideas from the North to the South, and that it may favor hegemony of science associated with Northern ways of thinking.

A post-structural researcher looks at language and palliative care practitioners have identified that language is an important component of defining what palliative care is. This study does not carry out a discourse analysis, although a glimpse at palliative care discourse with a lens of discourse theory has revealed that it is generally reductionist and may not consider all meanings around suffering - there is a large field of discursivity. No discourse should be a fixed entity and any hegemony of ideas should be exposed.

Laclau and Mouffe (1985) developed their discourse theory through the “deconstruction” of other bodies of theory. By deconstruction they refer to a careful reading of other theories which may uncover unrecognised or unacknowledged assumptions and internal contradictions, and I look at unacknowledged assumptions and internal contradictions throughout this study. Discourse theory may initially be unsettling as it aims to find flaws in other theories, but it ultimately aims to be affirming and to open avenues for new ways of thinking.

In the following chapter I continue my discussion around research methods and provide an overview of the data generation.

CHAPTER SIX

A methodological foray

6.1 Introduction

In this study I gathered data from two sources, namely from a nurses' palliative care curriculum and from caregivers who practice palliative care in rural homes. The bulk of this chapter considers methods used to gather data from caregivers. To my knowledge the data collection method has not been used before in this context and requires detailed explanation.

Prior to this study, my research experience had been situated within a positivist paradigm where a major consideration in research involves issues such as validity, reliability and generalizability of information (Toma, 2006). In medicine the "gold standard" of a study is the randomized control trial, which is based on the assumption that researchers can develop and apply perfect tools in wholly objective ways and can generalize from samples to broader populations (Toma, 2006, p. 405). Aoun and Kristjanson (2005) challenge palliative care to look beyond the evidence-based medicines' randomized control trial to new research frameworks. They advocate for a qualitative approach that hears the subjective stories of individuals and suggest we combine knowledge sourced in different ways if we wish to do our job well. In this study I work qualitatively.

Bean (2006) tells us that we are seduced by research as a beatific process by which we can glimpse the bright light of pure knowledge, and describes shadows that appear during our search for the bright light. I do not see research as seeking a bright light of pure knowledge, but I recognize that shadows may be cast over the research process. A shadow may be cast when research participants experience psychological barriers to free flow of ideas and are unable to articulate what they want to say. In this study participants (caregivers) may be anxious around talking to a Western, white, medical doctor. They may be wary that I am associated with management structures of their HBC care organizations and may not wish to place their organization in a bad light. I later describe the HBC organizations and provide some descriptions of caregivers.

Bean (2006, p. 353) advises researchers that creativity may assist in dispelling some of the shadows; when researchers and study participants are being creative, ideas may flow more readily than otherwise. If the world were static we would not need to be creative: what worked in the past would continue to work in the future. Creativity has at its heart a sense of play – of suspending normal constraints so as to see new patterns, possibilities or connections. In this research I wished to allow caregivers to be creative and “play” for a while. In this chapter I review a method for looking at a palliative care curriculum. I discuss gathering data for this study from caregivers and highlight my research position within the study. I discuss sites, caregivers, ethical issues, the research method, data management and issues around rigour in qualitative research as defined within a critical paradigm.

6.2 Gathering data from a curriculum

I look at data from a palliative care curriculum as a source of knowledge about palliative care. In general nurses have been practising as nurses prior to experiencing a curriculum for palliative care, and it may be that their experiences of practicing palliative care are shaped by many factors external to a curriculum, including, for example, their experiences of death in their own family. Their experiences of palliative care may also be shaped by their prior nursing experiences, their age, gender and own health. In the context of this study it is not unlikely that nurses themselves may be HIV positive, and this would impact on how they experience caring for other patients who are HIV positive. While acknowledging the multiple factors which could potentially impact on experience of palliative care, in this study I hone in on a palliative care curriculum and juxtapose what the curriculum says about palliative care with what caregivers say about palliative care. I was not present when caregivers experienced the palliative care curriculum, so the data I present around their experiences are a second-hand account of a curriculum. I cannot be certain about what they say about a curriculum.

In looking at a framework for exploring and presenting data from a nurses` palliative care curriculum I draw on the work of Pastrana *et al.* (2008). In their comprehensive discourse analysis of palliative care literature they conclude that palliative care is described according the four themes: target groups, structures, tasks and expertise. A target group refers to the type of patient who is offered care.

Structure refers to where care is carried out and for the purposes of this study I hone in on what curriculum says about where care is carried out. Roles refer to what caregivers do when caring and expertise refers to the specific type of caring which is offered as part of palliative care. I make use this framework to explore and present data from curriculum, as illustrated in Table 3.

Themes identified by Pastrana <i>et al.</i> (2008)	What does curriculum espouse?
Target groups	Who is cared for in palliative care?
Structures	Where is care carried out?
Tasks	What are the tasks of caregivers?
Expertise	Should caregivers be experts? Should palliative care be specialized care? If so, what type if expertise is required?

Table 3: Representation of themes identified by Pastrana et al. (2008)

6.3 Gathering data from participants

Vithal (2003, p. 115), working in a critical paradigm, characterizes “crucial descriptions” as being vital for the critical researcher. Such descriptions include an idea of transparency which makes visible the conditions as reviewed by the researcher. In the interests of transparency, I reiterate my position within the study. I am a white, European medical doctor and it could be assumed that I am an “outsider” to caregivers who are African nurses and HBC workers. Yet I have worked in rural KwaZulu-Natal, South Africa for 20 years and could be also an “insider.” Qualitative researchers gather detail through multiple, usually interactive methods, identifying and systematically reflecting on their role in inquiry and acknowledging and accommodating personal biases, values and interests (Cresswell, 2003). I am aware that my position as a researcher would make an impact on generation, gathering and interpretation of data (Ritchie & Lewis, 2003). I fully agree with Merriam (1999) that it is vital that a researcher explores and highlights her position in order to explore the complexities of research across cultures and context.

6.3.1 The researcher being researched: Shattering dreams

I have a personal reason for deeply exploring my research position, which I share with the reader in the story below.

Shattered dreams

A few years ago two male professors of medicine arrived from America and contacted me as they wanted to write a book about experiences of doctors working within the AIDS epidemic in South Africa. I readily agreed to be interviewed and was excited because I felt I had a lot to say about AIDS and felt that someone was going to listen to me.

I drove for two hours to meet the professors in a hotel in Durban and I met them in a small, darkened conference room. They wore thick coats and the air-conditioning was turned on full blast. I was wearing a thin dress and got cold quickly. I got colder, and colder and colder.

I answered their questions and told them what it was like working as a doctor in rural KwaZulu-Natal. I was freezing and they kept asking me questions. They kept staring at me. I started crying and their eyes lit up when I cried. They leaned forward to ask me more questions. The interview took one hour.

I glanced briefly at their book when it was published; they called it *Shattered Dreams*? The professors said “*Laura Campbell, who had done a special diploma in palliative medicine, wept as she told of an experience that seemed to epitomize what doing AIDS work had become for her*”(Oppenheimer & Bayer, 2007, p. 113). I had wept because I was cold. I had wept because I was angry at myself for not being able to tell these men that I was cold. I did not weep because of my AIDS work. I felt misunderstood, and abused. My dreams of being special and of being listened to were shattered.

I had felt disempowered and abused as a research participant - and I was determined that those I researched would not feel a similar sense of disempowerment and abuse.

6.3.2 The researcher researching: Not shattering dreams

My first concern related to my ability to know about the worlds of the participants and I reflected on the views of Tinker and Armstrong (2008) that the researcher must be part of the social group he or she is studying in order to truly understand what participants experienced. They note that this is particularly the case with communities that are disempowered or marginalized as outsiders cannot comprehend or represent their experiences. I am not part of the social group of people whom I intended to research and I was concerned that I could not comprehend the participants or accurately represent their experiences. I had to be sensitive to the fact that participants maybe suspicious of research carried out by a Western woman. I also had to be concerned whether I would understand them and whether I could possibly cause harm during or after the research process. Maykut, Maykut and Morehouse (1994) say that the researchers' experience is perhaps a paradoxical one as it is to be accurately tuned into the experiences and meaning systems of others and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand.

6.3.3 Researching and caring and empathy

In her book *Caring: A feminist approach to ethics and moral education*, Nel Noddings (1984) provides insights into caring which may be helpful in delineating how I describe my researcher position. She describes that experiencing another person's reality as nearly as possible is an essential part of caring. She feels compelled to act on behalf of others. The researcher's position must be imbued with more than simply a desire to collect data. A facet of our research capability must be to exhibit a sense of care and concern to understand the others' possibility. In a "critical postmodern" approach, Tierny (1994) suggests that our research endeavours and research position need to be reformulated so that they include a capacity for empathy. Empathy would consider the views, wishes and circumstances of the other person, and development of trust is viewed as an essential element in facilitating collection of data. I had worked with many of the caregivers for several years prior to this study. I reviewed patients who they referred to me and gave them feedback on their patients. I was not involved with any training. I considered that my research position was both outside and inside, and I cared about the research and the researched.

6.3.4 Researching and a commonality of purpose

I coin the term a “commonality of purpose” to describe how I saw my research position. I believed that the purpose of the research was to enable me to act in the interests of the caregivers and patients. Data indicated that some of the caregivers also believed that the purpose of the research was to act in the interest of the caregivers; Jabu,²³ a nurse, said:

²⁴I’m telling you that you can make a difference. You can change the whole thing. Yes I am telling you. You remember the story and then we can have the problem alleviated.²⁵ (J 681-694)

Your research, at least there is somebody you can just give this to. You are just going to give this work to somebody and there will be serious eye-opener. They make the rules and talk, talk, talk. They never go down to find out. Where are the results, are we achieving anything? I’m a nobody in a big pool here. You are doing the research, you are going to give it to somebody and that somebody, maybe Minister of Health, they are not stupid to see . (H1 642-663)

Ya, ya, ya, we all want this research to be a success. (H5 724)

I came to care deeply for and about the caregivers, and I believe they came to care about the purpose of the research. My research position was from a commonality of purpose. I intended to write up the study, present it to the caregivers and together present the findings to their managers and to curriculum developers, and together look at a way to ensure that the voices of caregivers were heard and acknowledged. As I discuss later when presenting the thesis data, I indicate that I needed to rethink this idea of commonality of purpose.

²³ I use pseudonyms throughout this study.

²⁴ When quoting caregivers I include an initial and numbers from the transcript, which will assist the reader to distinguish these data from other text.

²⁵ Jabu refers to a story I had told her about a child walking along a beach:

It was a stormy day and the waves pounded against the shore. The storm was so severe that the fish were washed up onto the sand and gasped for air. A little girl was walking along the beach and saw the many, many fish gasping for air. She threw one back. She threw another one back. Her father came along and said, “There are so many you cannot save them all.” The little girl replied, “But I can save this one.”

6.4 Study sites

The study took place in a rural area of KwaZulu-Natal, South Africa, which was selected for several reasons, including that there is a high prevalence of HIV and AIDS, there is a need for palliative care, and there is a lack of literature on palliative care curriculum in this context. In addition, I had been working in this area for many years and volunteered at a local hospice where I was known to nurses and to HBC workers. Where this study was carried out there is one hospice which employed five professional nurses, and four of these nurses had experienced a palliative care curriculum (which I will describe at length shortly). These nurses in turn work closely with HBC workers, who are employed either by hospice or affiliated HBC organizations. As I was interested in palliative curriculum I specifically approached a hospice where nurses had experienced a palliative care curriculum. I could find no statistics on the numbers of nurses who have experienced this curriculum, but to my knowledge there are few sites that employ nurses who have experienced a palliative care curriculum and who work in rural homes

6.5 Selection of caregivers

A positivist paradigm employs several methods for selecting a sample from a larger population. The aim of such a sample is to ensure that all cases are selected in such a way as to be representative of the larger population. The temptation is to apply these same principles to qualitative research, and then to judge qualitative studies (which usually have a smaller and less randomly selected sample) as being less scientifically rigorous. This study involved exploring conceptions of caregivers who had been exposed to a curriculum for palliative care. I specifically wished to include caregivers who practice palliative care in a rural, HBC setting as I wished to provide a space for “alternative voices”. Lather (1991) says that alternative voices may undermine the priority usually given to the agendas held by powerful people in society.

Palliative care is a relatively new discipline and few caregivers have experienced a curriculum for palliative care. As such, I used a purposeful sampling technique which selects information-rich cases for in-depth study. Purposeful sampling is considered to be appropriate in qualitative research: choosing participants because they are interesting, convenient or exemplary (Toma, 2006, p. 419).

Since there were only four nurses who practice home-based palliative care in this rural context and who had experienced the palliative care curriculum, those selected for possible inclusion in the study were considered to be information-rich. This method of selecting participants is common in qualitative research (Toma, 2006, p. 419). I made a decision to also include HBC workers who worked closely with these nurses, as I was aware that the hospice ran a training programme for HBC workers and these nurses facilitated the programme. I acknowledge that I made a large and perhaps unsubstantiated or unfounded assumption that HBC workers could have indirect experience of the palliative care curriculum which the nurses had experienced. I assumed that they gained knowledge about palliative care from the four nurses, and I made this assumption in an effort to increase data sources as there were so few nurses who had direct experience of a palliative care curriculum.

I explained the aims of the study to managers, who in turn informed nurses and HBC workers of the study. I stated that I wanted to interview nurses who had experienced the palliative care curriculum as I wanted to find out about their daily experiences of providing palliative care in patients' homes. I also invited HBC workers to participate if they worked with these nurses, as I explained that I also wanted to hear about their experiences. I requested caregivers to telephone me if they wished to participate, and thus I approached potential participants indirectly to minimize any sense of coercion that they may feel around the study. The managers were not aware of who participated.

Four nurses, representing all of the nurses who had experienced a palliative care curriculum in this context, approached me to participate. Five HBC workers who work closely with these nurses also agreed to participate (there are a total of 17 HBC workers who work closely with these nurses). All caregivers were Zulu and spoke Zulu as a first language and English as a second language. The nurses were professional nurses²⁶ and all had been nursing for more than 15 years. They had postgraduate qualifications in aspects of nursing which included psychiatry, obstetrics and community health.

²⁶ In South Africa there are differing categories of nurses. Professional nurses have attended an accredited Nurses Training College which is usually affiliated to a university. They have studied for at least four years.

6.6 Ethical issues

6.6.1 Informed consent

I obtained permission to conduct this study from the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee (Appendices A and B). I explained to both managers and caregivers that the study aimed to explore the experiences of people who had experienced a curriculum for palliative care. I explained the nature of informed consent and that receiving informed consent from participants has been highlighted as an important ethical issue (Mason, 2002). “Consent forms” and “Study Information forms” were available in both English and Zulu. Prior to giving written consent, I informed caregivers of their right to anonymity and confidentiality and indicated that a translator was available if they felt they required one. Caregivers indicated that they did not require the services of a translator. I let them know that they could withdraw from the research process at any time, and highlighted that I would provide feedback on completion of the study.

As I explain below, caregivers in this study were asked to take photographs to describe their experiences when practicing palliative care at home. I stressed to caregivers that their photographs would not be used as a direct method to elicit data, rather as a reference point to be used in subsequent discussions when I discussed photographs with them. In other words, the photographs were not used as primary data, rather as a form of “production data” in which the interviews around photographs were analysed as primary data sources (Mitchell, 2008). Caregivers were aware of who participated as I held group training sessions around the method, which included information on ethical issues and on the use of disposal cameras, which were held at a local community hall.

I informed caregivers that they should not take photographs of sick people as it would be intrusive and insensitive, and I emphasized that photographs of patients were not required for research purposes. Caregivers were requested to try and avoid taking photographs of people, and if they wished to take photographs of people then they must take the photograph in such a way that the person could not be identified (e.g. they could take a photograph of the back of a person’s head, or hand, or clothing only after obtaining informed verbal consent). Caregivers were fully briefed on issues of consent and were informed that they must make use of a “photographic information sheet” before taking any photographs.

This “photographic information sheet” was written in Zulu and was used by the caregiver when they wanted to take a photograph in a patient’s home. The photographic information sheet explained why the caregiver wanted to take a photograph and explained that only the researcher would have access to photographs. Visual data (especially photographs produced by participants) are often subjected to more rigorous scrutiny by ethics boards than most other data (Mitchell, 2008). In this study, to ensure that both participants and their photographic subjects were not placed at any risk, I presented all photographs to a research ethics committee, who were the final arbitrators of which photographs could end up in the public domain.

Caregivers were informed that after the research was completed neither they nor their photographic subjects would have access to any photographs, that some photographs may be used in reports and all other photographs would be held in safe-keeping before being destroyed after five years.

6.6.2 Place of interview

I carried out the interviews in a private room away from the caregivers’ place of work, and interviews were carried out outside office hours. I wanted caregivers to feel as comfortable as possible and considered that interviewing at a place and time away from work may help them feel at ease. Having a safe and private environment in which data are collected is important.

6.6.3 Confidentiality

Throughout this study, to preserve anonymity, I deliberately superficially describe the caregivers as I place emphasis on the need to protect their confidentiality. I was aware of the possibility of issues around breach of confidentiality, such as deductive disclosure. Deductive disclosure is also known as internal confidentiality. Tolich (2004) notes that deductive disclosure occurs when the traits of individuals or groups make them identifiable to others who read research reports. One of the most famous cases of deductive disclosure involves Carolyn Ellis’s ethnographic research in the book *Fisher Folk* (Ellis, 1996).

Ellis' data from a remote community allowed participants and others to identify themselves, and relationships in the community consequently became strained. Qualitative researchers face unique and often ambiguous ethical dilemmas in disseminating data about their study participants.

Palliative care is a very new discipline in a South African context and few nurses have experienced the palliative care curriculum; if my descriptions of participants included details on their age, gender, professional role and training then others would be able to recognize their individual voices.

6.7 Research method

I used a visual method for generating data and explain reasons for this below. Research in palliative care may be challenging due to the sensitive nature of issues associated with serious illness, dying and death and the potential vulnerability of both palliative care providers and researchers. Palliative care providers may be vulnerable because of the high level of stress associated with the ongoing physical and emotional burdens of caring for a sick person; the research process may heighten the vulnerability of palliative care providers as they relive traumatic experiences through the retelling of their experiences (Stevens, Lord, Proctor & O'Riordan, 2010). Researchers may also be at risk of experiencing vicarious trauma or emotional exhaustion (Dickson-Swift, James, Kippon & Liampottong, 2008). Researchers must obtain detailed information in an ethical way, without adding to the burden of those who care for patients, while at the same time protecting the participants and themselves.

6.7.1 Photography as a research tool

Traditionally, qualitative methods involve interviews, focus groups or participant observation, while other methods use narratives (story-telling) and a variety of visual techniques in order to engage participants actively in the research process. Visual research methods, including the use of photography, are increasingly used in the study of health and well-being, and two commonly used methods involve photography - photo-voice and photo-elicitation.

In a critical paradigm, photo-voice is a community-based participatory action research method as used by Wang, Cash and Powers (2000). This method invites participants to take photographs that, in their opinion, highlight features of a particular issue important to the community. The photographs are then discussed in a group setting, supported by researchers and with three main goals: to enable people to reflect on their communities' strengths and weakness; to promote critical dialogue and knowledge; and to reach and communicate with policy makers who can be mobilized for change. Wang, Yi, Tao and Carovano (1998) used photography as a data collection method and found that through photography, women living in rural villages in China were able to communicate important health messages to policy makers.

In South Africa researchers have begun to use qualitative visual research methods such as photo-voice to examine the issues surrounding community groups affected by HIV and AIDS. The majority of these studies have used the photo-voice technique in critical, participatory action research. Mitchell, deLange, Moletsane and Stuart (2005) used photo-voice in a rural region of KwaZulu-Natal to stimulate small group discussions amongst teachers and community health workers about their work with young people, focusing on HIV and AIDS. The same technique was also used to encourage discussion of HIV and AIDS amongst school children and to identify key themes surrounding this issue (Moletsane, deLange, Mitchell, Stuart & Buthelezi, 2007). In photo-voice the participants and researchers work together in a group to make sense of photographs taken by participants and together advocate for transformation.

In contrast, photo-elicitation is a method in which photographs taken by the researcher, or research participants, are used as a stimulus to facilitate discussion around the context of the photograph in subsequent interviews with individual participants (Firth & Harcourt, 2007). The aim of this study was to explore the experiences of nurses and HBC workers on an individual level, and for this reason I felt that a photo-elicitation technique was more suitable than the group-based photo-voice technique.

I also believed that the technique would be useful in a context where the researcher does not share the same native language as the participants. Kahn and Cannell (1957) suggest that a lack of familiarity with the local language on the researcher's part could interfere with various elements of the conversation as well as the researcher's comprehension of the participants' responses.

I thought that caregivers may feel more comfortable talking in English if they were discussing their photographs rather than holding traditional face-to-face interviews. By using photographs I hoped to put participants at ease and provide a basis for discussion of sensitive issues. I aimed to make the study enjoyable for participants. Other studies have shown that participants were enthusiastic photographic researchers and had fun taking pictures (Carson *et al.*, 2005). I wanted participants to be able to “play for a while”. Bean (2006, p. 362) discusses the importance of creativity in research: the shadow in research appears when one confronts the lack of creativity in research and psychological barriers to free flow of ideas (Bean, 2006, p. 363). Creativity has at its foundation a sense of play - of suspending normal constraints so as to see new patterns, possibilities or connections (Bean, 2006, p. 363). Play can be a great expression of seriousness (Neill & Ridley, 1995).

The use of photographs to represent participants’ conceptions may allow a natural introduction to issues through the use of metaphors and symbolism, and I believed this may be useful given the metaphorical nature of much of communication among Zulu people. As an illustration of the use of metaphors, Ellis (2004, p. 3) describes one of his Zulu patients:

His world has a wholeness which does not divide his mind from his body. His dreams, his feelings, his telepathy and his visions are all part of his tangible body... He expresses himself in stories, in metaphors and in symbols, which are mostly embodied and expressed in a physical form.

I asked caregivers to take their own photographs - a technique called auto-driving (Heisley & Levy, 1991). Throughout the study I regarded the photographs not as a method to elicit factual information, but rather as a reference point to be used for discussion in one-to-one interviews. I trained caregivers in the use of disposable cameras and requested them to take photographs of situations which they felt allowed them to express their daily experiences of offering palliative care. Each camera allowed 28 photographs, and in early 2010 the caregivers were given two weeks to take their photographs. After two weeks I had the photographs developed and set up individual participant interviews. I simply requested that caregivers to discuss their photographs with me, and thus data were collected from unstructured interviews which centred around photographs. The interviews were tape-recorded and transcribed into text by me and a research assistant.

The accuracy of translation was checked by a research assistant. Interviews lasted one hour each.

6.7.2 Researcher's reflections on the method

Many of the photographs were of poorly constructed buildings and gardens, and caregivers used these photographs to depict their experiences in trying to meet the social needs of their patients and in dealing with issues around patients being ostracized due to fear and ignorance around the spread of HIV. Participants also took photographs of gardens to depict that part of their work involved encouraging people to grow food. Photographs of clinics opened discussion around experiences when patients were supported or not supported by nurses at clinics. Photographs of posters opened discussions around their experiences of providing health education, and a photograph of some clothing prompted discussion around the rape of a young child.

In some instances caregivers took photographs of objects which at face-value seemed to be totally unconnected to their experiences, views or opinions of palliative care. For example, caregivers took photographs of traffic lights, bridges, libraries and roads. However, their discussions around their photographs revealed how they used metaphors in linking these objects to their tasks in caring for people at home. For example, a participant took a photograph of a stark tree and discussed the photograph:

Look at this tree. It is bare, without leaves. It is alone. The birds come and sit in the branches and abuse it. I want to cut down this tree because it is so alone and so abused. (N 520-522)

Further discussion around the tree led to the participant recounting painful memories of caring for her young, sick sister, and she highlighted the usefulness of the photo-elicitation method:

The photograph made me want to tell you (N 524).

The method appeared to increase caregivers' awareness of issues such as patients' rights: a caregiver took a photograph of a poster of "Patients' Rights" in a clinic setting which he had not noticed before. He felt that the poster was not available to patients:

So this thing was hiding on another wall because when you hit passages, you hit passages, you hit passages. I don't know why it was hiding I don't know. Why it was at the back, why they never stick it in the front where the people they can see. When I read them I said to myself these are rights and have to be known in public. They have to talk, if they are not satisfied they have to talk; they have to read because these things are there for them. (B 539-542)

Literature stresses the unprecedented importance of imaging and visual technologies in contemporary society, and urges researchers to take account of these images in conducting visual research (Mitchell, 2008). Although visual imaging and visual technologies may not be prominent in rural areas of South Africa, I felt that a visual method of photo-elicitation did enable the production of data around a relatively unexplored, potentially sensitive area. Photo-elicitation offers a way for participants to take the lead in discussions and it may have enabled them to hone in on issues which they felt were of importance to them in their daily work.

There are qualitative methods other than visual which may be of use in diverse cultural and spiritual contexts; for example, narrative research has been used in palliative care research (Thomas *et al.*, 2009) and may be of particular relevance in rural South Africa where there is a strong oral tradition.

6.7.3 Caregivers' reflections on the method

Several caregivers commented that the photographs would allow future generations to have insight into their experiences and circumstances, and felt that photography as a means of historical record-keeping was important. Two caregivers spontaneously reported that they enjoyed taking photographs:

It was a wonderful experience and I wish I can get another opportunity to take more pictures because now I learnt how to take pictures, now I know what to take, how to take it. (B 570-572)

Another described how he found the method to be empowering for him:

It was empowering me because it's like taking someone else's job who went to university for journalist. Ya like a journalist or something now. (C 54-58)

Several caregivers highlighted challenges around taking the photographs, which included being refused entry to healthcare facilities. One stressed that there was a necessity to fully explain the research method to healthcare managers:

It was difficult because people they need to know why you want the photographs. What you is going to do with them, but I explained to them, they understand because it's the people I always used to work with them, they know that I can't do anything wrong. (Z 35-36)

They also reported that patients and their families also required a full explanation of why photographs were being taken and were concerned that the photographs may be sold for profit. The caregiver had to stress that only the researcher would have access to photographs and they would not be sold for profit.

6.8 Data management and analysis

Terre Blanche *et al.* (2008, p. 321) note that the key to doing a good qualitative analysis is to stay close to the data and interpret them from a position of empathic understanding. The anthropologist Clifford Geertz (1993) said that the purpose of qualitative analysis was to provide a “thick description”, which means a thorough description of the characteristics, processes, transactions and contexts that constitute the phenomenon being studied, couched in language that is not alien to the phenomenon, as well as an account of the researcher's role in constructing this description. A useful aphorism in qualitative research is to make the familiar strange and the strange familiar.

Terre Blanche *et al.* (2008, p. 322) note that there are several steps in interpreting qualitative data. The first step is familiarization and immersion. In managing data and presenting it in a coherent manner, I read the transcribed tape-recordings repeatedly to familiarize myself with the text, to have a full picture of the data collected and to begin to identify main themes throughout such reading.

A second step is inducing themes. Induction means inferring general themes for ideas from specific instances. It is a “bottom-up approach” which does not involve fitting data into predetermined themes (a top-down approach). In inducing themes the researcher looks at the material and tries to work out organizing themes which “naturally” underlie the material. I attempted to use the language of the caregivers as much as possible to label themes. I attempted to move beyond merely summarizing content and presented themes in terms of tensions and contradictions in data. In some instances contradictory data were produced by more than one caregiver, and in other instances one caregiver appeared to contradict herself. I tried to find what Terre Blanche *et al.* (2008, p. 324) term “an optimal level of complexity”. Having two or three themes was not enough to illustrate the experiences of the caregivers.

A third step is elaboration. In elaboration themes are organized until the researcher feels she can give a good account of what is going on in data. In this study themes which emerged from caregivers’ experiences (an interactive curriculum) were pieced together and juxtaposed with the nurses’ palliative care curriculum (a preactive curriculum) to form a picture of their knowledge source and collective experiences of palliative care practice in rural homes. This elaboration focused on curriculum as a source of knowledge around palliative care while acknowledging that many other factors could have acted as a source of knowledge of palliative care.

The analysis took several stages. I worked for several weeks with the data in an attempt to understand it as deeply as possible. On the first attempt at analysis I analyzed the data in terms of the appropriateness, benefits and challenges of both palliative care and home care, and then looked to see whether the curriculum mentioned such benefits or challenges. This analysis formed several chapters of this study. However, on reflection I realized that this analysis did not provide the reader with a deep, critical understanding of how caregiver data converged with or diverged from the palliative care curriculum or how caregivers mediated the curriculum. The final analysis reviews how caregivers’ data converge with and diverge from curriculum data.

6.9 Validity in qualitative research: Rearticulating quantitative notions of validity and reliability

I briefly discussed validity and reliability in qualitative research in Part One, Chapter One, and I expand on this discussion below. Before I explore qualitative research let me expand on quantitative notions, and then I will hone in on how qualitative notions differ from these.

In a quantitative realm issues such as reliability, validity and triangulation are used to determine whether a study shows rigour. Terre Blanche *et al.* (2008, p. 152) define reliability as:

The dependability of a measurement instrument; that is the extent to which the instrument yields the same results in repeated trials.

Kirk and Miller (1986) identify three types of reliability referred to in quantitative research, which relate to the degree to which a measurement, given repeatedly, remains the same; the stability of a measurement over time; and the similarity of measurements within a given time period. Hesse-Biber & Leavy (2011, p. 48) describe validity as “*how do you you’re your findings are plausible and will be received as a credible explanation or interpretation of the phenomenon you are studying?*” Traditional criteria for validity find their roots in a positivist tradition and, to an extent, positivism has been defined by a systematic theory of validity. Within the positivist terminology validity resided amongst and was the result and culmination of other empirical conceptions: universal laws, evidence, objectivity, truth, actuality, deduction, reason, fact and mathematical data, to name just a few. Joppe (2000, p. 3) provides the following explanation of what validity is in quantitative research:

Validity determines whether the research truly measures that which it was intended to measure or how truthful the research results are. In other words, does the research instrument allow you to hit "the bull's eye" of your research object?

Patton (2002) states that validity and reliability are two factors which should concern any qualitative researcher while they are designing a study, analysing results and judging the quality of a study. This corresponds to the question that “How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?” (Lincoln & Guba, 1985, p. 290). To answer this question, Healy and Perry (2000) assert that the quality of a study in each paradigm should be judged by its own paradigm's terms.

While the terms reliability and validity are essential criteria for quality in quantitative paradigms, in qualitative paradigms terms other than reliability and validity are used, for example, catalytic, concurrent, consequential, construct and content validities, to name a few (Cohen, Mannon & Morrison, 2011). Some view validity of data as the “correctness of research interpretation” (Ritchie & Lewis, 2003, p. 107). Others see validity as an effort to improve understanding of data rather than improved accuracy (Malterud, 2001).

In qualitative research there is a need for some kind of qualifying check or measure for research. As a result, many researchers have developed their own concepts of validity and have often generated or adopted what they consider to be more appropriate terms, such as authenticity and trustworthiness. Throughout this study I aimed to describe context and data in such a rich way that others would have noticed and recorded it in the same way (Stake, 1995). Cohen *et al.* (2011, p. 185) describe an idea of authenticity in which the research should provide a fresh understanding of a situation, e.g. making the familiar strange. Brock-Utne (1996) describes the role of authenticity in research in reducing “cultural blindness” in that research should act to make visible important cultural issues in a context.

One of the important strengths of qualitative research is an idea of generativity - that is, the study constructs new ways of understanding and the reader acts to apply findings from this study to their own context. Throughout this study I rely on and adhere to Gay and Airasians (2003, p. 536) checklist for validity and reliability in qualitative research²⁷.

²⁷ Is the researcher's relationship with participants described? Is field documentation comprehensive, fully cross referenced and annotated, and rigorously detailed? Where the observations and interviews documented using multiple means? Is the interviewer's training documented? Is construction, planning and testing of all instruments documented? Are informants described? Are sampling techniques documented (Gay & Airasian, 2003, P. 536).

6.10 Conclusion

In this chapter I opened with a description of the methods I used to gather data from a palliative care curriculum and explained that I acknowledged that a curriculum could not be regarded as a sole knowledge source on palliative care. I stressed that data I generated from caregivers with regard to the palliative care curriculum represented a second-hand account of curriculum, and as such cannot claim to be certain about the curriculum. A data collection framework considered four aspects of curriculum: who is cared for, where caring occurs, roles of caregivers and whether expertise is required for palliative care practice.

In gathering data from caregivers I reiterated a need for qualitative research when looking at palliative care curriculum and practice in context. In particular, qualitative research may provide creative means for data generation and research participants may become more creative when “playing”. I highlighted a need for transparency in critical research and made explicit what I saw as my research position. Taking account of my personal experiences of being researched, I took care to ensure that caregivers were not disadvantaged and could view the research to be of use to them. I described my research position as “a commonality of purpose” and provided an overview of study sites and, taking heed of a possibility of deductive disclosure, provided a superficial description of participants. Ethical issues were seen as important and I described issues around informed consent, place of interview and confidentiality.

I provided an overview of methods I used for participant data generation, which were twofold. In the first phase participants were requested to take photographs which they felt enabled them to describe their daily experiences when practising palliative care; and in the second the researcher and participants discussed photographs and these discussions were tape-recorded. This method is referred to as photo-elicitation, which I employed within a critical paradigm. This data collection method was generally useful in generating data, but did have drawbacks. Data were analyzed using thematic induction - themes arose spontaneously from discussions around the photographs.

I deployed notions of authenticity, trustworthiness and transparency and ask the reader to place themselves in the footsteps of myself and the caregivers. In the vein of generativity, I ask would they analyze and make sense of data in the way that I do?

PART FOUR

Working with data

This part focuses on data used to explore the first three study questions which involved curriculum as a knowledge source, caregivers' experiences of context and their experiences of palliative care practice. This part comprises four chapters and data are presented in three chapters. In the first of these three chapters, a curriculum for palliative care is reviewed as a direct knowledge source for palliative care for nurses and an indirect knowledge source for HBC workers. This review of curriculum is carried out in themes as identified by Pastrana *et al.* (2008), namely: who is cared for, place of care, caring roles and expertise in palliative care. In the second and third chapter, data are presented from caregivers around their experiences of the context and experiences of their practice of palliative care respectively. In the fourth chapter the data are juxtaposed with published literature in order to deepen meaning and understanding.

CHAPTER SEVEN

Curriculum as a knowledge source

7.1 Introduction

This chapter addresses the first study question: What knowledge informs caregivers' palliative care practice in rural homes? This question explores curriculum as a source of palliative care knowledge used to prepare caregivers for palliative care practice. The caregivers who participated in this study were trained using a curriculum which I refer to as "the nurses' palliative care curriculum", and I provide an overview of this curriculum as representing a broad palliative care discourse.

In the previous chapters I highlighted that I was interested in a situation where a curriculum developed in one context was introduced into another context. In a Northern context, palliative care developed in the 1970s as a new way of caring to replace the old way of caring where patients who faced death were believed to be neglected and shunned by caregivers. There is a lack of consensus around palliative care, and in looking at a framework for exploring and presenting the nurses' palliative care curriculum I draw on the work of Pastrana *et al.* (2008). In their comprehensive discourse analysis of palliative care literature they conclude that palliative care is described according to four themes: target groups, structures, tasks and expertise. I open this chapter with a background to the nurses' palliative care curriculum and then hone in on an analysis of curriculum data, which is presented in the four themes.

7.2 Background to the nurses' palliative care curriculum

The nurses' palliative care curriculum was developed in 2009 and I cannot provide information around how it was developed, since this information is not available in the literature and I was not involved with development of the curriculum. The curriculum is presented as a joint venture between the HPCA, South Africa and Foundation for Professional Development.²⁸ The full title of the curriculum is "Distance Palliative Care Nursing for Professional Nurses". The nurse is expected to carry out learning and tasks without direct, continual supervision and attends lectures at a designated Centre for Palliative Care Learning. The curriculum says that "The medium of instruction and assessment of this course is ENGLISH [capitalized in the curriculum text] (Assessment guide: 9). The curriculum advocates that palliative care be offered as part of an "inter-" or "multi-disciplinary" team (Vol. 1, p. 41).

7.2.1 What caregivers say about the course

The four nurses who were participants in this study all attended a training course during 2009, and the document used to support the training was the nurses' palliative care curriculum. During data collection, while discussing their photographs, they discussed practical issues of their course: who ran the course, where the course was carried out, what teaching methods were employed, who attended, content of the course, and how students were examined. I present some of the discussions below.

Sister Francis²⁹ trained us. She is a white nurse based at Themba Hospice.³⁰ (J 323)

²⁸ Foundation for Professional Development (FPD) is a South African private institution of higher education established in October 1997 by the South African Medical Association. The vision of FPD is to build a better society through education and development. The mission of FPD is to ensure the availability of skilled professionals, allied workers and managers who will be able to deliver a service to the public that is affordable, evidence-based and congruent with international best practice.

²⁹ I remind the reader that I use pseudonyms.

³⁰ Themba Hospice is a pseudonym.

I did the training at Themba Hospice. It was a little bit difficult. It is not a difficult course but there is a lot of work to be done in a short period of time and we were not full-time students. We were working and only had one day to go and attend our classes. There was practical work that needed to be done. Lectures were given on Thursday. We had to do our practical work at the hospice including night duty. (T 40-43)

We used to travel there. We would leave here at seven and reach there after eight. (T 42)

We started with five nurses and one left so only four completed. (L 22)

I believe that the content of the course was enough, although sometimes the exposure was inadequate. The course was mainly on cancer and there was little done on HIV and AIDS and meanwhile we are concentrating on HIV and AIDS. The course was more relevant for people that are dealing with palliative care for people with cancer. (T 57-60)

You expect to get higher marks but you need to write a lot to get higher marks. (T 54)

Nurse learners were trained by a person who was not from the same culture and were trained at an urban site which is away from their place of work in a rural site. Teaching methods included lectures and practical work. Only nurses attended the course, and they were trained by another nurse. Nurse learners felt that the content of the course was adequate, although they commented that there could have been more emphasis on HIV and AIDS. Nurses were examined in a written examination format.

7.2.2 An overview of the structure of the curriculum

The curriculum comprises five text documents: four modules and an assessment guide. The titles and number of pages per module are summarized in Table 4 below.

Module number and title	No. of pages	% of the total
1. Principles and practice of palliative care	117	20
2. Pain and symptom control	309	54
3. Basic communication skills in palliative care	69	12
4. Psychosocial, emotional and spiritual issues in palliative care	81	14

Table 4: Curriculum module and number of pages per module

The curriculum also gives a “rough guide to study time” for each module, as illustrated in Table 5.

Module number	Title of module	Suggested allocated time
Module 1	Principles and practice of palliative care	12 hours (12.5%)
Module 2	Pain and symptom control	43 ½ hours (45%)
Module 3	Basic communication skills in palliative care	18 hours (18%)
Module 4	Psychosocial, emotional and spiritual issues in palliative care	22 ½ hours (23%)

Table 5: Curriculum module and suggested study times

7.2.3 Theoretical underpinning of the nurses' palliative care curriculum

The nurses' palliative care curriculum states that it operates with "a process model as advanced by Stenhouse" (Assessment guide, p. 13):

This framework has been chosen based upon the quality of the journey rather than the exclusivity of the destination and curriculum content is chosen for its worthiness in providing examples of key concepts.

This is reflected in the concepts of palliative care, in that the carer is aiming to provide quality for the remainder of the patient's life (or journey) for the patient, and the family and the course member is learning from principles (or key concepts) which may be transferred to their own context.

Stenhouse was opposed to a didactic form of teaching where learners are presented with a version of knowledge developed in the disciplines, which they passively learn. In his opinion, having been instructed in a disciplinary way, the end product is that the student now has this knowledge and if tested on it they would be able to show that they have it. Disciplinary knowledge, for Stenhouse, is not a series of knowledge bytes to be consumed by the learner, but a body of knowledge with its own logical structure and form. Stenhouse's curriculum may be regarded as a practical curriculum and, as such, would be expected to consider practice in context. Caregivers suggested that their course enabled them to reflect on aspects of their daily practice within their context:

We used to share more than anything about the culture. I think Sister Francis has an open mind. She said that African people have their own rituals and they should be allowed to practice those rituals because those are the rituals. (J 332-334)

I now use the framework derived from the work of Pastrana *et al.* (2008) to present the curriculum text on target groups, structures, tasks and expertise in palliative care.

7.3 Analysis of the nurses' palliative care curriculum

7.3.1 Who is cared for?

The nurses' palliative care curriculum identifies the target group (who is cared for) as people who have a life-limiting illness or life-threatening illness (Vol. 1, p. 19). A target group for palliative care is also identified as "patients and their families, for whom cure is no longer an option" (Assessment guide, p. 12).

7.3.2 Place of care

In several instances the espoused curriculum notes that palliative care should be delivered within a hospice setting (Vol. 1, p. 21). Curriculum advocates for the home as an important and "ideal" place of care, and I illustrate this with two specific examples:

South African hospice programmes provide palliative care particularly for patients with advanced, progressive disease, mainly cancer and HIV/AIDS. The focus is on home-based care and extends into the bereavement period. (Vol. 1, p. 21)

The ideal model for delivery of palliative care in Africa appears to be
The provision of home-based care services working within the existing
community health structures. (Vol. 1, p. 82)

The nurses' palliative care curriculum explicitly links home care to "an ideal model of care." The word "ideal" implies perfect, supreme or best. The use of the word "model" is complex, as a model can imply either a perfect situation or a typical, replicable situation. In the curriculum, home care is thus implied to be either the best type of care and/or a replicable type of care. The curriculum describes that if home care cannot meet all the patients' needs, then a hospital will be an appropriate place to meet needs, although no evidence is provided to support this:

Although, in most cases the patient can be supported at home,
there will be situations when admission to a hospital is indicated. (Vol. 1, p. 82)

The above statement suggests that home care can be supported by hospital care - and I reiterate that no evidence is provided to support this statement.

7.3.3 Caregivers' functions

I provide a brief overview of the nurses' curriculum presentation of roles in terms of the curriculum scholar Basil Bernstein. He implies that the way language is used within a particular societal class affects the way people assign significance and meaning to the things about which they are speaking. The significance of an aspect of a curriculum can be reviewed in terms of emphasis or weightings given to the various curriculum dimensions (time, space and discourse and evaluation). In a curriculum there is organization of time into study periods. He calls each period of defined time a "unit" and suggests that time allocation gives subjects a status; the more time a topic has, the more important it is perceived to be. In a critical stance, Bernstein is concerned with the effects of a curriculum:

How a society selects, classifies, distributes, transmits and evaluates the educational knowledge it considers to be public, reflects both the distribution of power and the principles of social control. (Bernstein, 1971, p. 47)³¹

Throughout the curriculum numerous roles were identified for caregivers, including pain and symptom management, psychosocial care, spiritual care and cultural care, and I discuss these below.

³¹ In his "Classification and Framing" article (1971) Bernstein analyses the structure of three curricular "message systems". Firstly, he distinguishes between a *Collection* type curriculum and an *Integrated* type curriculum. In the "Collection" code, subjects have very distinct boundaries and are well insulated from each other. Subjects are kept apart. In the "Integrated" code, there is little insulation of subjects. The curriculum may be based on themes - for example, in the primary school, a theme like "Transport" may include the *history* of transport. Secondly, Bernstein introduces the concepts of *Classification* and *Frame*. Classification does not refer to what is classified, but to the *boundary strength* between what is classified. Strong Classification means strong boundaries, such as when the timetable consists of clearly separate subjects, e.g. Science and Mathematics. Weak Classification refers to weak boundaries between the subjects. Strong Classification is characteristic of the Collection code; and Weak Classification characteristic of Integrated code. Thirdly, "Frame" refers to the message system of pedagogy. Do teachers and pupils control content, how it is organised, how it is sequenced? A curriculum with rigid topics, to be completed in a predetermined order, within a specified time, would represent strong framing. Weak framing would occur when the teacher is able to select topics on the basis of pupil interest, or some other such principle, and organise the sequence and pacing of material according to pupil readiness and stage of development. Classification is associated with *power* and Framing is associated with *control*.

7.3.3.1 *Pain management*

In the curriculum, pain and symptom control were identified as a key role for palliative caregivers, and Module 2: “Pain and Symptom Control” is devoted to these roles and forms over half of the total curriculum text. In Bernstein’s terms, the largest time allocation in the curriculum to pain and symptom management implies that these roles have a higher status than other roles.

7.3.3.2 *Cancer care*

In several instances the curriculum discusses a role for caregivers in caring for patients who have cancer:

For palliative care patients with cancer, the appropriate and judicious use of anti-cancer therapy is sometimes the most effective means of controlling pain. (Vol 2, p. 47)

Cancer is not one disease but many (Vol. 2, p. 49)

Pages 207-232 in Volume 2 are dedicated to the role of the caregiver in cancer care. There was also discussion around caring for children and people with the following diseases: motor neuron disease, multiple sclerosis, cardiac failure, lung disease, liver disease and Huntington’s disease. Huntington’s disease is rare. There was notably little discussion around a role for caregivers of patients who have HIV disease and AIDS.

7.3.3.3 *Telling about death*

The espoused curriculum proposes that a role of a caregiver involves telling a patient “the bad news” about impending death, as illustrated in the following two instances:

The learner must be able to demonstrate ability to handle difficult situations and break bad news to patients and their families in a sensitive, caring manner. (Assessment guide, p. 19)

There is evidence from many different countries and cultures that terminally ill patients fear the unknown more than they fear the known and will suffer less both physically and psychosocially when they are given the information they want, (Vol 1, p. 53)

No evidence is given to support the above statement.

7.3.3.4 *Psychosocial care*

The nurses' palliative care curriculum describes the role of caregivers in psychosocial care in Module 4 and devotes two pages specifically to psychosocial needs (Vol. 4, pp. 17-18). In the curriculum a theory of "Maslow's hierarchy of needs" is presented as a framework for a caregiver to review a patient's needs (Figure 2). Maslow's hierarchy of needs is a theory by Abraham Maslow in his 1943 paper *A Theory of Human Motivation*. The hierarchy of needs is often portrayed in the shape of a pyramid, with the largest and most fundamental levels of needs at the bottom, and the need for self-actualization at the top.

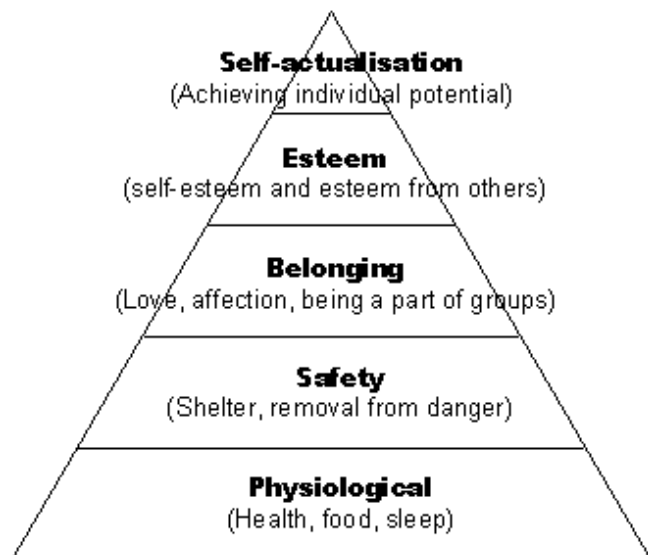


Figure 2: Maslow's hierarchy of needs

At the bottom of the pyramid are physiological needs, and these are the requirements for human survival. If these requirements are not met, the human body simply cannot continue to function: air, water and food are necessary for survival. Clothing and shelter provide necessary protection from the elements. On the next level are safety needs, and when their physical needs are relatively satisfied, the individual's safety needs take precedence and dominate behaviour. After physiological and safety needs are fulfilled, the third layer of human needs is social and involves feelings of belongingness.

This need is especially strong in childhood. Humans need to feel a sense of belonging and acceptance, whether it comes from a large social group or close family members, intimate partners and mentors. At the next level is self-esteem, all humans having a need to be respected and to have self-esteem and self-respect. The top level, self-actualization, pertains to what a person's full potential is and to realizing that potential. Critics of this pyramid of needs have suggested that it favours individualistic ways of looking at the world at the expense of collective ways of doing so (Hofsede, 1984).

In the nurses' palliative care curriculum there is relatively little text allocated to the role of a caregiver in assessing and managing psychosocial needs in context, and in terms of Bernstein psychosocial care could be regarded as being of less value than pain and symptom control.

7.3.3.5 *Cultural and spiritual care*

The espoused curriculum advocates that roles of a caregiver should include cultural and spiritual care of the patient. Such issues invite discussion around a wide diversity of cultures, religions and spirituality, particularly in rural Africa where culture and religion may take on more significance in daily life than in other societies. I acknowledge that a curriculum may be a document that people can take away and read in their own time, and it would be impossible to include all issues of importance in caring for sick people in one document. However, in the curriculum text only a total of six pages at the end of the fourth module are allocated to cultural care. This represents 1% of the total number of pages, and cultures which are considered in these six pages are African, Christian, Hindu, Jewish, Muslim and Buddhist. Five pages of text are allocated to spiritual care (Vol. 4, pp. 57-61).

Part of caring for a person is to respect their cultural and religious belief systems. I grew up in a tormented time in Northern Ireland and am aware of the importance of beliefs and culture as the conflict during my youth centred on intolerance and ignorance around religious beliefs. Differences in beliefs have caused deep, dangerous conflicts throughout history and throughout the world. A relative neglect of cultural and spiritual aspects of care in the curriculum text could be construed as almost patronizing, and it could be viewed that curriculum designers condescended to include topics which they believed to be of little relevance. Caregivers implied that a decision to include discussion around beliefs hinged on the discretion of the trainer:

We used to share stories and things and even the events, the examples of what happened. We used to share and Sister Francis and I were close. The others used to laugh at her because she said that the rituals should be allowed but I am quite aware that some people's rituals will not let other people be comfortable. (J 353-354)

In Jabu's perspective above, the lecturer facilitated discussion around culture and Sister Francis discussed it because she "has an open mind". The lecturer's views did not appear to be accepted by all the students. Another caregiver describes that she felt the lecturer did not include enough on cultural or spiritual aspects of caring:

Practically the course did not involve much on people practising traditional medicines. You never invited the Sangoma. You never invited the Inyanga. ...They just invited pastors in a Western kind of religion and they never involved African religious leaders. (T 80-81... 100-101).

It appears that a decision around whether to include discussion around issues such as culture or spiritual care depended on the individual lecturers. The data strongly suggest that lecturers excluded people who may know about African cultures and religious beliefs. This is a particularly salient piece of data, as I show later that culture and spirituality are of paramount significance in this context. It is indeed noteworthy that caregivers felt that those who know something about African beliefs were excluded from their curriculum experience.

7.3.4 Specialized care

Earlier I discussed that there was ongoing discussion about whether palliative care should be offered as a specialized type of care or not. In several instances the espoused curriculum reports palliative care as a specialized type of care:

Caring for patients and their families, for whom cure is no longer an option, is rapidly developing as an area of medicine and nursing which requires specialist skills and knowledge in order that patient and their families receive optimum care at a physical, psychological, social and spiritual level. (Assessment guide, p. 12)

The view that palliative care is specialized care is reiterated in the aims of the course:

The Short Course in Palliative Nursing seeks, through the process of education, to enhance and promote the principles of practice of palliative care in a variety of settings, by equipping registered nurse practitioners with **specialized skills** and a basic knowledge on palliative nursing care.

(Assessment guide, p. 13)

The nurses' palliative care curriculum introduces palliative care as a new type of specialized care in South Africa, and describes that the concept was introduced following a visit by Dame Saunders in 1982 (Vol. 1, p. 23). Placing palliative care as specialized care implies that providers should be experts in care. In a positivist realm, specialization and expertise place a high emphasis on evidence-based practice. The curriculum suggests that that palliative care should operate within evidence-based practice, as illustrated in several instances:

Palliative care is essential, scientifically sound and accessible to all terminally ill patients and depends on the participation of families. (Vol. 1, p. 83)

To be “scientifically sound” an evidence base is required, and an evidence base requires definition and standardization, and the curriculum emphasizes a need to understand a definition of palliative care:

Understanding the definition and being able to apply it to the care of patients is very important. Definitions are often something that we read at the beginning of a chapter and then forget about. In palliative care, however, these definitions shape the way we provide care and therefore you need to be able to understand them and be able to apply them as you work through this course. (Vol. 1, p. 20)

In some instances, seeking concise definitions can be of use and concise definitions can be found in the work of people who think in a positivist framework. However, in some instances seeking concise definitions can make assumptions that all things are definable. Some things may be definable in palliative care, such as the dose of morphine required to relieve pain in a particular patient. However, particularly with palliative care some things do not lend themselves to rigid definition, for example spiritual care. The curriculum prioritizes positivist thinking since it explicitly states that we must be able to define something in order to work with it. I discuss later in Chapter Ten that this palliative care curriculum was not specific to care in rural homes in Africa.

7.4 Conclusion

This chapter explored study question number one: What knowledge informs palliative care providers in rural homes? I provided an overview of the nurses' palliative care curriculum as it was the preactive curriculum experienced directly by nurses and indirectly by HBC workers. I assumed that as palliative care may be a novel idea in this context, the curriculum would represent a relatively important knowledge source, while acknowledging that it would not be expected to be the only source of knowledge.

The curriculum was presented by a lecturer from a different culture to the learners, and was presented in English which is the second language of the nurses. The curriculum was presented at a site which was distant to the site of practice, and a nurse lectured other nurses.

The espoused curriculum reported that a target group for palliative care was patients who have a life-limiting illness or incurable disease. Curriculum text advocated that palliative care can be delivered in hospices, homes and hospitals, and prioritized home care. It espoused that medical care (hospitals) would act as an appropriate back-up for home care.

Curriculum designers emphasized the role of a caregiver as pain and symptom control with relatively less emphasis on psychosocial, cultural care and spiritual care. The espoused curriculum advocated that a patient should be told of imminent death. There was relative inattention to the role of caregivers in specifically caring for patients who have HIV and AIDS. The curriculum noted that palliative care should be specialized care; definitions and evidence-based practice were described as important.

Curriculum designers appeared to make an assumption that the basic needs of patients would be met, since some aspects of palliative care appeared to be offered at the highest level in Marlow's hierarchy of needs, and this assumption may not hold true in rural homes. Issues such as patients needing information could be regarded as higher than basic living and safety needs. It is important to seek the views of people who have experienced this palliative care curriculum, as enacting such a curriculum may pose challenges if, for example, people face starvation and their fundamental psychosocial needs are unmet.

In the following chapter I present data around caregivers' experiences of the context.

CHAPTER EIGHT

How caregivers experience the context of care

8.1 Introduction

This chapter looks at study question number two: How do caregivers experience the context of palliative care? This question explores what it would be like to be a caregiver providing palliative care. In their experiences, what are homes like? What support is available? What are their main challenges and how do they feel about them? This chapter attempts to build bridges of knowledge between caregivers, researcher, curriculum designers and the reader:

Each person is an island unto himself, in a very real sense;
and he can only build bridges to other islands if he is first of
all willing to be himself and permitted to be himself.
(Rogers, 1961, p. 21)

As I explained previously, I employed a method of photo-elicitation in which caregivers took photographs to depict their experiences of a context and of practising palliative care. In this chapter I present data around their experiences of the context and in doing so I wish to build bridges of understanding between the caregivers, myself and the reader. The reader will note that most data come from the nurses rather than HBC workers. To enrich the reader's understanding of the context, I have inserted some of their photographs into the text and, using caregivers' own words, I aim to illuminate what could it be like to provide palliative care in this context. What are patients' homes, family life, resources and beliefs like?

In terms of exemplarity (Vithal, 2003, p. 116) these caregivers serve as an example of other caregivers who may work in rural, isolated areas. I aim to indicate to the reader the complexities and challenges associated with a tangled web of social, cultural, economic and healthcare issues in context.

I discuss the following: challenges in meeting basic living needs, complexities in family life, difficulty in securing financial resources, traditional beliefs, complications in caring, and caregivers becoming distressed.

8.2 Challenges in meeting basic living needs

Jabu³² (a palliative care nurse) poignantly provides an overview of caring in context:

³³What I've experienced when you go and see the patient who needs for more than just to me to show my face. I wish I had food just to give this person. I wish I can have a place where I can take this patient to be looked after. I just find the person there lying there very dehydrated in the hot weather and the shack can fall at any time. There is no grant, there is nothing and then we've got this food parcel. Who is going to cook for this person? I wish I can have a place to just temporarily to place this patient, you know to be well looked after ... (J 379-385)



Figure 3: A photograph outside a rural home

Jabu illuminates the profound challenges of her context. Neither she nor her patient can be certain of where the next meal will come from. She cannot be sure that this shack can withstand a blistering wind and shelter from a blistering hot, African sun. She cannot be confident that the basic needs of her patients can be met. Lungi (a palliative care nurse) also discusses patients' homes:

³²I use pseudonyms for caregivers throughout the study.

³³ Just to reiterate that when I quote from data, I use an initials and numbers from the transcript; this will assist the reader to discern data from other text.

The community that I nurse, most of them stay in such homes, those mud houses without any windows that's why they've got TB

[tuberculosis]. (L 233-235)

These are the houses; you see there's no ventilation. This is a mud house, it has no windows and it falls down on the other side. (L241-244)

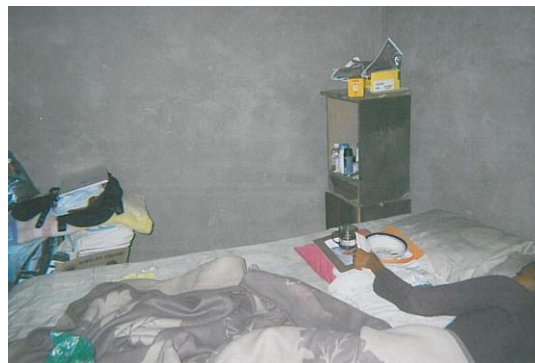


Figure 4: Photograph depicting inside a home

Lungi indicates that she cares for people who live in makeshift, temporary, unstable houses. The houses are built of locally available materials (mud), suggesting that the occupants cannot afford other building materials. A lack of windows may result in such homes being dark inside and may prevent adequate ventilation; people cook indoors using open fires and a lack of ventilation can make people susceptible to airborne diseases (such as TB). She cannot be assured that her efforts to treat an infection such as TB will be successful as the environment greatly increases the risk of acquiring infection or reinfection. The caregiver cannot be sure that she will not contract an infectious disease herself when working in such homes. Sindiwe (an HBC worker) also discusses patients' houses:

They are poor. The house they are staying in is full of water on the ground. I don't know how the water gets there but there is water running inside the house. There are holes in the walls. Look at the mattress outside. It is outside because inside is full of water. (S 102-104... 172)

Thandeka (a palliative care nurse) illustrates that some people may live in homes that are not shacks and have a shack as part of their property:

Look at this photograph, this is not something uncommon. It is something that is common to most of the nurses that work here. You find that at times they don't even want the person to be inside their house, they keep the patient in a shack outside the main house because they fear that he's going to infect their kids. (T468-472)



Figure 5: Photograph of sick person inside a shack

People may have a specific part of their home reserved for those who are ill, and the sick are excluded from family life. The family may isolate the sick as they are ignorant and fearful of transmission of illness, and fear that they may contract an infectious disease either directly or indirectly from the ill person. Thandeka intimates that isolating the sick to a shack is a situation commonly encountered by nurses when providing palliative care in patients' homes. She cannot depend on a family to take care of an ill relative.

8.3 Complexities in family life

Caregivers provide insights into complexities associated with contemporary family life. In the past in rural areas families used to care for their ill relatives:

Families used to take care of their own. For example, we traditional Zulus have had our own traditional herbs that could help the patient. You know like if the patient had a sore they were able to put some herbs to heal it, if the patient had diarrhoea they had medicinal substances that they could prepare and give to the patients. (L 320-323)

When a family finds that they can no longer care for the person then they rely on another family to take care of them. Here, for example, a caregiver discusses a vulnerable child:

So this little girl is dumped by another girl to this family. Can you imagine the woman in this house has got four children already and this new baby is only 18 months old when she is dumped on to this family? The uncle is sick and tired of looking after the baby, so I had to take it to the crèche. (J926-930; J945-947)



Figure 6: Photograph of young child in need of care

Jabu intimates a need to understand apparent neglect of a child in terms of the complexities of context; a young girl is introduced into a home without prior negotiation and the family is burdened by the addition of another mouth to feed. People may not have access to financial resources. She sees the multifaceted face of caring and understands the despair faced by those in this family. She sees how deprivation and the high burden of care can lead to contradictions in that the family may want to provide care but just cannot. This could lead outsiders to regard their reluctance to provide care as being uncaring or neglectful. The caregiver cannot be sure that an abandoned, vulnerable child will be cared for by relatives. A high burden of care in an area of profound deprivation may lead to challenges, frustrations and tensions in family life, as illustrated in the following instances:

This lady told me that she is taking TB treatment here at the hospital. So she left the child with her father. The father do this rape on this child. The lady didn't see what's happening to this child and she noticed after that there is something happening to the child because the child only stay crying and crying and this lady told me and I try to transfer that problem to the social workers. (S150-154)



Figure 7: Photograph of baby in need of care

Sindiwe discusses the rape of a young child at home by the child's father and her discussion speaks of the devaluation of young children and of the role of women as "gate keepers"³⁴ protecting young, vulnerable children from harm. Other participants also discuss rape of children (J933-935) (S442-444). Their discussions provide a window into the complexities of caring in a context of intense social need. With specific regard to children, a caregiver is compelled by South African law to report any instances of suspected child abuse to their supervisor or to the authorities. To do so a caregiver may have to travel a long distance and wait a long time at a police station to report her suspicions. Police may not take action. The family may become upset because she has reported her suspicions and may lose faith in her intention to offer care. There may be instances when confidentiality must be breached; for example, if a patient discusses that her young child has been abused, in confidence with a nurse, the nurse is obligated to report the matter. The child may retract statements of abuse and perhaps face increased abuse from a perpetrator. The caregiver could potentially put the child, family and herself at risk of harm if she reports a suspected incidence of child abuse. An intention to protect a young child may be thwarted by context.

The caregivers illustrate that family care within a context of a larger community support system, is important:

We are doing mostly home-based care and if the patient is well supported in the community then symptoms like pain can go away naturally. (L74-75)

If a person has a strong support system in the community then challenging issues, for example pain, can be lessened. This speaks of the importance of the community. Community support can act as potent analgesia and community support, acting as a "natural" way of caring, is congruent with age-old practices of care in Africa.

³⁴ By gatekeeper, I mean someone who controls access to something of value.

8.4 Difficulty in securing financial resources

Caregivers described a lack of financial resources and difficulties in securing financial resources for patients. They alluded to resultant effects of poverty; for example, extreme poverty compels people to rely on others for basic living requirements:

This family they haven't even got a garden, a vegetable garden, just to put a few rows of spinach, a few rows of carrots, they depend on the neighbour for food. We give them the food parcel but it's not enough, it's very little but because they are on treatment you've got to give them whatever you've got. (L 337-241)



Figure 8: Photograph depicting lack of resources

Lungi refers to a patient taking “treatment” possibly for HIV/AIDS or TB, as these two diseases are the most common in her context. Treatment for HIV or TB should be taken with food; when medications are taken on an empty stomach the patient may experience nausea, vomiting and diarrhea, and consequently medications may be poorly absorbed and rendered ineffective. Medical care is complicated and compromised by a lack of basic nutrition. She cannot be assured that the treatment will work if the patient is starving. She infers that she gives patients money from her own pocket, “you give them whatever you’ve got.” She cannot isolate her care to just nursing care as she sees the profound social needs; the patient’s problems become her concerns. Caring in this context may potentially have a financial impact on the caregiver.

Jabu discusses why there may be a lack of funds in rural areas:

In the rural area, where there is no infrastructure, nobody wants to go there ... Most of the NGOs³⁵ and the Government is just concentrating on the urban area and neglecting this thing. People say - Oh no, our vision³⁶ won't let us go there. There is no time. It is wasted going there. Yet that is where the problem is, in the rural area where there is nobody. Where I'm coming from the people don't even have a home place and there are places where there is not even a clinic. I sometimes I feel sad because I'm helping people just for the bread and butter issue. In my community there is nobody else that so helping them.

(J 405-412)

Jabu suggests that little attention has been paid to the specific needs of those who live in inaccessible rural areas. In her view, people from Government and privately funded organizations use excuses to remain in urban areas, for example, organizational policy decisions (it is not in our vision), time constraints or belief that work in a rural area is not fulfilling, "it is wasted going there." An emphasis on care in urban areas may appear to be uncaring and biased against people who live in rural areas. However, from an organizational view, working in a rural area may be difficult as it may prove to be expensive for an NGO to operate in a rural area, access may be problematic and supervision may be difficult. Poor, marginalized people may be unable to coherently articulate their needs to the NGO. NGOs may not be sure of who represents the community, as there may be breakdown in traditional leadership and decision-making structures. In the past Zulu social structures involved clear delineation around who could act as a leader and make decisions on behalf of others. In rural areas a social structure referred to as "*umndeni*" refers to all the people staying in a homestead who are related to each other, either by blood, marriage, or adoption. Most rural households comprise extended families, brothers with their wives, unmarried sisters, children, parents and grandparents all staying together in the same homestead. The Zulu family is patriarchal; a man is both the head of the family and the figure of authority.

³⁵ A non-governmental organization (NGO) is a legally constituted organization created by natural or legal persons that operates independently from any government and is a term usually used by governments to refer to entities that have no government status. In cases in which NGOs are funded totally or partially by governments, the NGO maintains its non-governmental status by excluding government representatives from membership in the organization. The term is usually applied only to organizations that pursue some wider social aim that has political aspects, but that are not overtly political organizations such as political parties.

³⁶ Jabu refers to the Vision Statements of NGOs.

In the past an elderly male would act as decision maker for the *umndeni*; however, with the HIV epidemic many people do not live with their relatives and traditional social structures have disintegrated. Securing financial resources in rural areas is not straightforward.

8.5 Importance and challenges of traditional beliefs

Caregivers illustrate that an important component of family life in rural Africa relates to peoples' beliefs around traditional religions, rituals and practices:

There is a great number of our African people who now go to Shembe³⁷ religion because it allows them to practice their own Africa cultures like slaughtering, like wearing traditional attire, like having polygamy and using traditional medicines. (T 109-117)

People appear to greatly value their traditions and appreciate avenues which allow them to continue practising their cultures and there is a wide diversity of religions; a caregiver specifically mentions the Shembe Church which is unique in Zulu culture, and earlier Thandeka mentioned that her curriculum experience did not include involvement from a leader of an African church (T 80-81).

³⁷Shembe: The Shembe Church is an African Initiated Church founded by Isaiah Shembe 1910. It has approximately 4 million members. It differs from mainstream Christianity in that polygamy is permitted and animal sacrifice is practiced in religious ceremonies.

8.5.1 Beliefs around death

Jabu discusses some beliefs around death:

I think that on the African side the family as such, no not the family - the clan - they used to acknowledge oh there is a death in that family and that there is a certain way that is expected for them to behave. For instance, especially if I have lost my man, my husband, I'm not allowed to go to the social gathering the family. The women should be quiet; there should be no fighting and no rising of the voice. (J 289-294)

Even in peoples' homes you will find to use a certain paintings to show that we are mourning. After one month we have to slaughter a goat to cleanse the family. The people then are allowed to attend the social gathering but you as a woman you have to mourn the whole year. It used not to be the black clothes, the black clothes it came with the Western. (J296-299)

Jabu's discussion highlights the need to be aware of local customs, as an outsider may mistake silence and social isolation as a profound a psychological problem such as severe depression.

Additionally, practices, such as slaughtering a goat could be seen as cruel and primitive to an outsider who is unaware of the value of slaughtering animals in traditional beliefs. Earlier Thandeka stated that her curriculum experience did not include issues around culture (T 100-101).

8.5.2 Beliefs and male hegemony

Jabu's discussion exemplifies how beliefs and practices around death may be gendered, in that widows are expected to adhere to traditions and women who are mourning the death of their male partner must be subdued, silent and socially isolated. Jabu also notes that recently widowed women are not allowed to be in close contact with cattle; cattle may be held in higher esteem than a woman who does not have a male partner:

If I'm going somewhere and there is a flock of cattle and then I'm not allowed to go through that flock. (J 294)

The customs are mainly for women who must be seen to be mourning. A man is just expected to wear a black belt for one month or three months. What people do depends on the family. A man is not expected to mourn for too long. They used to have this belief that a man should get married before the gall bladder bursts, so the quicker the better. (J317-322)

Jabu discusses that the traditional customs are directed at women rather than men, for example, a man wears a small cloth symbol to signal that he is mourning, is not expected to mourn for as long as a woman, and is expected to remarry soon after the death of his wife.

8.5.3 Beliefs and cure

Caregivers highlight that patients believe in miracles and believe that their illness can be cured. This can lead to some difficulties for the caregiver if she explains that the illness can probably not be cured:

It is hard to explain this to the family as when they see a nurse coming to the house they expect that nurse must do miracles and do wonders and heal this person... (T138-142)

So you go to the person and say
“Rest in your bed and just wait for nature to take its course”. It’s very difficult to explain to our own Africa people because we always believe there is a miracle going to happen. You go to the Inyanga³⁸. You still believe that there is an Inyanga who can do a miracle and get me cured. (T 1013-1016)



Figure 9: Photograph depicting a patient

³⁸ An inyanga is a traditional Zulu healer.

8.6 Complications in caring

Caregivers described some complications and challenges they experience when caring for patients.

8.6.1 Ambiguity of role

Caregivers express ambiguity about their role and the family's role in caring:

There are those who expect you to do the whole thing now. They expect you as a nurse to bath that patient; to come and feed that patient and to come and change the dressing ... They just don't want to do anything for that patient. (T687- 691)

The family believes that the nurse has arrived to fully care for the patient and relieve them of their responsibility for care. The family may be poorly educated and misunderstand the role of a nurse in this context and may believe that she has arrived to specifically relieve them of their duties. The family may be worn down by caring and may see that despite all their efforts, the patient's condition continues to deteriorate. There may be some blurring of boundaries and lack of clarity around what comprises family care, community care and palliative care.

8.6.2 Not knowing the cause of an illness

Caregivers also describe that care can become complicated when they don't know the cause of an illness:

Hey, look at this one. I am scared. Can you see what this is? It is a sore on someone arm. This lady is very sick and I have never seen this thing before. It is rotting. It smells. I see sick people but this one is different, she cries when we clean it. (S 236-242)

I am frightened even to help her. I am frightened but it is my job. I have to do it ... I am frightened of her disease. I don't know how she got this. (S 300- 302)

This caregiver's discussion provides insight into the fears of caregivers and intensity of problems faced by their patients. This caregiver is faced with providing care for a rotting, smelling wound and she cannot be sure of the cause of the wound. She may be putting herself at risk if this wound is infectious. Both she and her patients are distressed. The patient has inadequate analgesia and cries each time the wound is cleaned. This situation hints at a lack of support for this caregiver; it seems like there is no one she can turn to for advice or assistance, and adequate analgesia is not available. She may have to work independently without adequate professional support, equipment or medication. She cannot be sure of what is causing this sore, and she cannot be sure that she is giving the correct treatment if she is not sure of the cause.

8.6.3 Not getting support

Caregivers show that they cannot always rely on support from other healthcare professionals when caring for a patient at home:

This patient went to the clinic. She doesn't want to go to the hospital. The doctors and the nurses at the clinic say that she must go to the hospital. She has been to the hospital many times and they do not admit her. She comes home late, she can't walk and she uses her money for a taxi. She has no money. (S 245-247)

8.7 Caregivers becoming distressed

Caregivers described that they felt scared (S 236) and frightened (S 300). They described other emotions while caring in this context:

I feel bad about those people living so hard, struggling but they can't do anything. There are no jobs, no nothing ... I feel bad, very bad. (S 149-150)

Sometimes you feel sick because you see these very painful things. (S 196)

Sometimes it's depressing when you try your level best. You think you have things under control but the person decides to give up and die. (T 1006-1007)

8.8 Conclusion

Caregivers experience palliative care practice in a context where patients live in abject poverty with little access to financial aid or social resources. They describe profound challenges in meeting the basic living needs of their patients. Their patients may need social care as they may be unsure of where their next meal may come from; they may not be sure that their shack will remain standing or will provide them with any shelter.

Caregivers experience the deep and multifaceted complexities of family life. They find that people may be abused, raped, neglected, stigmatized or ostracized. Patients are not always safe. Families may not always be in a position to offer care for their vulnerable relatives.

Caregivers experience that obtaining financial resources in rural areas presents harsh challenges as resources appear to be focused on urban areas. A lack of financial resources renders patients dependent on other people for basics such as food.

Patients may not map on to a worldview of modern society as traditional views are experienced by caregivers as important and prominent. Although traditional ways are valued there are instances when traditional views conflict with contemporary society as they may act to ensconce male hegemony.

Caring presents numerous challenges as caregivers were unsure of their role and unsure of a family's role in caring. The cause of an illness was not always known and lack of knowledge could lead to fear of contamination and transfer of infectious diseases. Such challenges were compounded by a lack of support from formal healthcare institutions such as hospitals. Such harsh, raw challenges led to caregivers experiencing feelings of uncertainty, fear and futility. In the following chapter, I will explore how the experiences of caregivers can impact on how they perceive palliative care. What do they say about providing palliative care in harsh conditions where people are desperate for social support?

CHAPTER NINE

Caregivers' experiences of practice of palliative care

9.1 Introduction

In this chapter I aim to address study question number three: What are caregivers' experiences of palliative care practice in patients' rural homes? This question attempts to fathom the ways in which caregivers experience practice of palliative care curriculum within their own context.

Caregivers provide care for patients in rural Africa where these patients can be geographically isolated from hospitals and from doctors. Their patients may be financially isolated from healthcare as they cannot afford the cost of travel to a clinic or hospital. As such, a caregiver may have to work in isolation with little access to diagnostic tests which may tell her what the cause of the patient's illness is. In an absence of diagnostic and prognostic blood tests and scans she may have to work with uncertainty, as she may not know how long a patient is expected to live and may be unsure of what is causing a problem as her patients may be starving, stigmatized and ostracized.

In South Africa most nurses will have trained and practised in a hospital context prior to working in patients' homes. A unique aspect of this study is a context of place of care where caregivers practice home-based palliative care, and caregivers discussed the home as a place of care at length. They also, to a lesser extent, discussed challenges and benefits of hospital care, their work and palliative care.

One data source was four nurses who had direct experience of the preactive nurses' palliative care curriculum. I remind the reader that this curriculum has been recently introduced into this context and may map onto a Northern societal view of palliative care. A second data source was five HBC workers who work closely with the palliative care nurses. As I explained in the previous section, I make an assumption that these HBC workers experienced an indirect preactive curriculum. These caregivers form a purposeful sample and as such the data they present are not representative of caregivers in general. The analysis produced four main themes, namely caring at home, caring in hospitals, the work of caregivers and palliative care in context.

The reader will again note that most data were generated by the nurses. The data are substantial, and each of these four themes has several sub-themes. To orientate the reader to these complex, rich data I summarize the main themes and sub-themes diagrammatically below in Table 6 below.

Themes	Sub-themes
Caring at home	Home care <ul style="list-style-type: none"> • Who is cared for? • Increased access to care • Humanizing care • Implementation of knowledge • Practice of traditional customs • Improving quality of life • Patients not valuing care • Dangers in caring • Not meeting expectations • Invisible care
Caring in hospitals	Hospital care <ul style="list-style-type: none"> • Withholding care • Impersonal care
The work of caregivers	<ul style="list-style-type: none"> • Social work • Pain and symptom management • Cultural work • Spiritual work • Communication work • Psychosocial and physical work
Palliative care in context	<ul style="list-style-type: none"> • An old idea masquerading as a new idea • A new idea for bereavement care • A new understanding of a medical condition • A new approach to preparing for death • Experts in physical care • Experts in theory and not in practice • A lack of expertise • Abuse of expertise • Scientific evidence-based practice

Table 6: Summary of themes and sub-themes that emerged from the data

9.2 Home care

In analyzing data around caregivers' experiences of home care, I considered what caregivers said about where they provided care. As illustrated in Table 1 several sub-themes arose within this theme, and I present each of these sub-themes in turn.

9.2.1 Who is cared for?

In looking at this sub-theme I reviewed what caregivers said about who they think they should care for or do care for at home. In most cases caregivers referred to the people they cared for as patients, and thus their view was that the cared for should be ill people. In two instances caregivers explicitly discussed who they provide care for at home:

We don't do it as you guys are doing it, you see? It's just we don't say OK because you are dying we have to let you die peacefully or alternatively we are not letting you die we are trying to save you. It doesn't happen like that We care for both the ones who are dying and the ones who are not dying. (Z 107-109)

Zanele (an HBC worker) draws a distinction between white people's (you guys) and Zulu people's approach around who to care for. In her opinion white people offer palliative care for those dying, whereas Zulu people do not offer their care exclusively towards the dying:

White people must look after their dying as it is how they do it. But we must be available for whoever needs us - that is how we do it ... White people have got their own ways to comfort their ill. White people have got words that they use to tell a person they are dying. We don't have a word that means to care for the dying ... In Zulu you take care of the living ones as well ... We use a word *Ukumakekela* which means to care for all the ill. (Z 94-124 122-123)

Zanele offers a Zulu word *Ukumakekla* which she sees as close to palliative care. In my literature review for this study I noted that curriculum designers may need to think about how they translate notions around palliative care into African languages. This discussion hints that there may be some challenges in translating the term "palliative care" as there may not be a Zulu equivalent.

A Zulu concept of care appears to include care of all; those who do not have an illness, those who do have an illness and those who are dying as a result of illness. Zanele draws a distinction between who white people care for and who Zulu people care for. She implies that palliative care targets care exclusively towards those who will die and *Ukumakekela* targets care towards both those who will live and at those who will die. Thus curriculum designers can expect some challenges when translating “palliative care” into African languages and we may need further deconstruction of the word “palliate”.

Lungi describes her care as not distinguishing between who will live and who may die and the cared for includes everyone:

We are giving them all the same care but you cannot identify the ones that are going to die because sometimes you find a very ill patient and miraculously they just recover. (L99-100)

The reason why Zanele and Lungi see a notion of care as including everyone may be due to uncertainty in their context of patient care: they do not know who will live and who will die; “you cannot identify the ones that are going to die.” Patients identified for palliative care are not necessarily about to die; for example, in the context of South Africa a patient who has HIV and access to ART could be offered palliative care and could also live a full, healthy, active life relatively unencumbered by their disease. In the home nurses may not have access to a doctor who will provide diagnosis and prognosis. Thandeka illustrates that within a medical context it is the doctor who prognosticates with a high degree of certainty and who assures when palliative care is required:

In hospital the doctors used to say no active resuscitation³⁹ and you say eish this person is getting to have a cardiac arrest..⁴⁰ I can see the arrest but I’m not going to resuscitate. (T188-190)

A doctor, using predictive knowledge, technology and medical science, can make a decision about withholding medical intervention; a caregiver at home may not be able to practice with such assurance:

³⁹ No active resuscitation refers to a written order in patients’ medical records. Usually a doctor makes a decision that if a person experiences a life-threatening acute event, such as a heart attack, then no effort will be made to instigate medical intervention, such as cardiopulmonary resuscitation (CPR)

⁴⁰ Cardiac arrest refers to a heart attack.

We are not sure who will die and who will live. Even if you are a nurse, even with all your experience, you cannot say this one will die or this one will live. (L 96-97)

We are giving them all the same care but you cannot identify the ones that are going to die because sometimes you find a very ill patient and miraculously they just recover. (L99-100)

At home it is challenging to be confident around whether a patient faces imminent death as a patient may be starving and their condition may improve if they gain access to food and shelter and if their stress of daily living is alleviated; a patient could “miraculously recover”. The curriculum did not consider leaving room for such doubts and uncertainties when practicing palliative care. This uncertainty is not a philosophical, theoretical uncertainty but rather a physical or material uncertainty.

A curative intervention may not always be medical; sometimes the patient is starving and would only need food (not medicine) to survive. In the absence of any prognosticating tools it may be possible that a patient could be offered palliative care at home and not be referred for potential curative intervention. There is no clarity at home on who should be cared for in palliative care.

9.2.2 Increased access to care

In the previous chapter I used caregivers’ voices to describe the context in which they care. They described that patients are poor and may have to use valuable financial resources to travel to a hospital. Hospitals may be far from patients’ homes, and when a patient reaches a hospital they may not be guaranteed admission. Home care may be useful as healthcare comes to the patient’s home; Jabu (a palliative care nurse) describes this helpful aspect of home care:

Then I just come and the family say “This person has driven all the way here to see me. They are coming to see me and they are going to address me with my name and everything”. (J 711-713)

A patient can be geographically isolated and have little access to the financial resources necessary to travel to a healthcare facility. Healthcare is thus available on their doorstep. This situation means that the caregiver becomes isolated.

9.2.3 Humanizing care

Caring in a context of home care has a humanizing effect on a patient, community and caregivers. I discuss each of these in turn.

The quality of patients' homes was not standard. The home seemed to be a useful place for caring in some instances, and several caregivers alluded to the importance of home care in allowing the patient to receive individualized, humanizing attention from a caregiver:

The patient says that the caregiver understands me and they listen to what I am saying. I just help them where I can and they feel human again. (J 705)

When you do the home visit you know the patient much better than anyone else. You know the home situation. You know the family members and everything. (J 749-751)

Jabu implies that the home, as a place for care, enables the caregiver to come to know about deeply personal issues such as the social conditions and family dynamics of the patient:

Home care is more sort of intense because daily it is what we do. We pack our bags in the morning, load them into our cars, go out into the community and see the patient from where they live. Unlike in a clinic or hospital where you just see somebody who is well dressed but you don't know the background or where they came from. In home care you see the dwelling, how they live, what they actually do, how they cook, what is the relationship to other members of the community. This is very important. You know when you arrive at a person's home whether she has support from people around her or is she being rejected. With home care we see the true picture. (L60-67)

Home care provides caregivers with an opportunity to enter into a patient's home and "see the patient from where they live." Specifically, home care is more beneficial than clinic or hospital care as a caregiver has a chance to see the patients "warts and all." In a hospital or a clinical setting a patient may attempt to hide issues which they feel may be embarrassing; for example, they disguise their poverty by dressing well. Some of the limitations of a clinic or hospital are exposed; the only information available to a doctor about a patient comes from the impression which the patient wishes to create or from questioning the patient or family.

The doctor relies on the patients' willingness and/or ability to describe their problems, whereas a home-based caregiver can infer the problem without having to ask potentially sensitive personal questions. Lungi's discussion speaks of the benefits of the home in humanizing the patient and seeing a person beyond their identity as a patient. Home care may permit the nurse to see a patient as more than a patient; she can see the patient intimately as a grandmother, mother, neighbour and community member. The caregiver can know of hardships, challenges, support and lack of support. This has a potential negative side as the caregiver may experience a sense of futility if she feels that she can do nothing to alleviate challenges. A caregiver can certainly experience the hardships of her patients, but may be uncertain about what to do. The palliative care curriculum seemed uncertain around harsh social issues as presented by caregivers in this context.

Secondly, caregivers implied that home care may also support a sick person within the familiar surroundings of their community:

We are doing mostly home-based care and if the patient is well supported in the community then symptoms, like pain, can go away. (L 74-75)

This caregiver implies that if a person has a strong support system in the community then challenging issues, for example pain, can be lessened. This speaks of the importance of the community as she implies that community support can act as potent analgesia and with strong community support medicines may not be required. Her discussion may allude to a "placebo effect"⁴¹ in which the power of thought can act to reduce physical symptoms. Community support would not be possible in the medical environment of a hospital, hospice or clinic. Community support acts as a "natural" way of caring and is congruent with age-old practices of care in Africa, given the historical absence of "Western-based" medicine or allopathy. It may allow the patient to experience a sense of belonging, and when the patient feels a sense of belonging they may be responsive to the efforts of others to assist them. Home care enables humanizing of the patient by the community.

⁴¹ The placebo effect refers to a phenomenon in which a placebo -- a fake treatment, an inactive substance like sugar, distilled water, or saline solution -- can sometimes improve a patient's condition simply because the person has the expectation that it will be helpful. Expectation plays a potent role in the placebo effect; the more a person believes they are going to benefit from a treatment, the more likely it is that they will experience a benefit.

Thirdly, home care can also be of benefit to caregivers in allowing them to feel needed, valued and humanized. Jabu illustrates this point:

I give myself a pat on the shoulders and say I have done a good job here ... It is so nice when you arrive at this house and they greet you. (J 699-703)

They have a stress on their faces and then when you leave they give you a smile. At least I know that I have made a difference to these people. (J 703-705)

Jabu enjoys visiting people in their own homes, feels appreciated by patients and values their appreciation. Perhaps in a busy hospital ward a nurse could not find time to pay such deep attention to her patients and would not experience the same sense of fulfillment in caring. She may be only one of many nurses who care for the patient and at home she is the sole caregiver and consequently may be deeply valued by her patients. In a hospital the nurse may be busy with duties such as dispensing medication, cleaning wounds, bathing patients and completing reports, and as such a nurse may be too busy to sit down and talk and listen. The patient is usually in hospital for a short time, whereas home care allows the nurse to visit often over a period of time: the caregiver and patient can come to know and value each other over time.

9.2.4 Independent implementation of knowledge

Within the context of this study, HBC enables a caregiver to independently implement her nursing “knowledge” and practice skills. Caregivers intimated that this aspect of home care was important to them:

I fell in love with it because it is so nice when you are a home-based care person. You have an opportunity to implement all your knowledge. When you are at a hospital, or a clinic you are just talking to the patient. (J 746-748)

At home a nurse experiences a sense of agency through autonomously implementing her nursing knowledge, whereas in hospital she may only implement her knowledge and skills under supervision or surveillance from more senior healthcare professionals.

It may be appropriate to practice in an independent way at home because there is limited access to supervisors or advisors; although this issue of independent practice seems important to caregivers, it was not raised in the palliative care curriculum. This nurse seemed to be very certain in her practice of palliative care at home, so there may be times that although the curriculum is uncertain, the practice may be certain.

In home care the caregiver can act in an independent manner without having to justify her decisions to people other than her patient and family. If she were in a hospital she may be observed by patients who lie in beds close to the patient she is attending. Patients may not understand decisions made by healthcare professionals and may feel upset by actions they don't understand. Thandeka illustrates this point:

The other patients they are just looking at you as a nurse and they are calling you, "Nurse! Nurse! This person is dying" and you just come and hold the patient's hand and the other patients say "Do something." They look on you as a cruel nurse really. (T 190-193)

At home Thandeka can let a patient die peacefully, without technological intervention, "holding the patient's hand". She does not need to face the confusion, opinions or accusations of other patients and does not have to justify her actions to others. However, her discussion suggests a need for supervision and checking as she may be placed in a situation where she is unsure about whether all that can be done for her patient has been done. The curriculum provided no guidance around this issue and seemed to assume that the nurse would always know when a patient was dying because treatment had failed.

9.2.5 Enabling the practice of traditional customs

The context of home care enables patients to practice traditional customs. In the previous chapter caregivers described how common and important such traditions are in patients' everyday life. I noted earlier that the palliative care curriculum relatively neglected cultural aspects of care in rural, African homes. Jabu provides an overview of traditional customs associated with bereavement, and by implication that knowledge of such customs is an important aspect of care:

I really don't know about the white and the Western people, the Western people you know what they've been doing. I think that on the African side the family as such, no not the family - the clan - they used to acknowledge oh there is a death in that family and that there is a certain way that is expected for them to behave. For instance, especially if I have lost my man, my husband, I'm not allowed to go to the social gathering of the family. The women should be quiet; there should be no fighting and no raising of the voice. (J 289-294)

Jabu assumes there is a distinction between bereavement customs of white and Zulu people. She is unsure of the white/Western traditions around caring for the dying. In regarding African customs to be different to Western customs, there may be a requirement for an intimate local sociocultural knowledge to make sense of local customs. For example, an outsider may mistake silence and social isolation as a profound psychological problem, such as severe depression, when in fact such behaviour is common and expected in this context. A Zulu-speaking nurse working in a home care context may have intimate socio-cultural knowledge, whereas a doctor at a hospital may not.

Home care may also enable access to traditional medicines, and caregivers discuss that patients make use of traditional medicines which are available in the local community and which would generally not be available at clinics or hospitals:

Families used to take care of their own. For example, we traditional Zulus have had our own traditional herbs that could help the patient. You know like if the patient had a sore they were able to put some herbs to heal it, if the patient had diarrhoea they had medicinal substances that they could prepare and give to the patients. (L 320-323)

Practice around traditional medicines that are certain in a rural home may become uncertain in a hospital context. Lungi discusses that family care involved using traditional medicines which were successful in treating common problems such as sores and diarrhoea.

If such medicines were useful in the past, then encouraging the use of these may facilitate empowerment of patients and their families so that they could offer care without relying on outside assistance.

9.2.6 Improving quality of life

A context of home care can lead to an improvement in a patient's quality of life as it allows a caregiver to keep visiting her patient even if the patient faces death, and this aspect of care is particularly important in a rural context where the patient may be unable to access any other form of health care. The caregiver can continue to care in the best way she can, whereas in a hospital a patient may be relatively neglected in a busy medical ward when they face death. Thandeka alludes to the home setting being of benefit as it offers ongoing care to the dying:

I used to work in a lot of hospitals and I wanted to get a feel of what it is like to work for a hospice and home care. I wanted to know how the home care approach differed from hospitals and clinics. I noticed that in clinics and hospitals they focused on curative care. While in the home you don't concentrate much on curative, you concentrate on the palliative aspect and mostly on improving the quality of life. (T 931-935)

Hospital care may allow for a certainty of diagnosis and prognosis as healthcare professionals can access diagnostic and prognostic tools, and a limitation of hospital care may lie in that care focuses on curative care and, in the opinion of this caregiver, curative care does not prioritize or lead to improving the "quality of life" of patients who face death due to illness. Home care advocates for a continued value of life irrespective of healthcare professionals' perceived hopelessness of the patient's condition; even though individuals have an incurable disease they should still matter because they are still alive.

This caregiver's view can be regarded as a false dichotomy in that she feels that curative care is not associated with "quality of life" care; both curative and palliative care could focus on improving the quality of life of the patient. In a home care context the caregiver can only be certain of the care she offers, as she cannot be certain if she is offering care to a patient who will live or a patient who will die.

9.2.7 Families not valuing care

At home patients may not value care provided by caregivers, and this point is illustrated by Thandeka:

They will be calling him a loved one once he's dead but when he is still suffering with them they just don't want to have anything to do with him. Once he is dead then it becomes a story that you took our family member, you took him to a Drop-in Centre⁴² and now you are coming and you are telling us that he's dead ... It's just a risk you take but you can't win because if you keep this person at home then there is no one to look after him. (T 480-495)

A caregiver may have to face a family alone without support, and the family may not understand or appreciate her efforts. This situation may arise in any context but may be particularly salient in an area where there is a high prevalence of HIV and AIDS. Let me expand on this. A family may act in what appears to be a hypocritical way as they espouse to love the dying person but, in contradiction to their expression of concern, they act in an inhumane manner towards him/her. This reflects the complexities of caring for a dying person and the complexities of human nature. Families may realize that the person faces death and, as a means of self-protection, distance themselves; it is best not to get close to someone who will leave. They may have experienced many losses and cannot face the pain of losing another deeply loved relative. When a person to whom they did not show care dies, their feelings and the memories of the bereaved may change; the "despised sick" becomes the "beloved dead." Perhaps the family espouses to love the deceased relative as they feel guilty about their treatment of him/her. The caregiver who attended the "despised sick" is accused of causing the death of the "beloved dead" relative.

The caregiver is therefore placed in a "lose-lose" situation. Caregivers may not always be sure that their care efforts are valued by other people; this issue was not raised in the palliative care curriculum.

⁴² A Drop-in centre in South Africa is a building attached to a hospital. It is usually staffed by nurses and informal caregivers. It may contain a few beds. The aim of the centre is to offer non-medical care (such as food, clothing, bathing).

9.2.8 Dangers of caring

Home care may be challenging, as in some instances it offers potential dangers to caregivers:

It's a bit dangerous, the safety of nurses. Sometimes you pass a group of young men and you are not sure if you are safe these days. They may hijack your car. (L 404-408)

Lungi uses a car to travel from one patient's home to another, and she expresses concern for her personal safety as young men may harm her if they steal the car. In a context of KwaZulu-Natal, hijacking is a common occurrence. In another instance Jabu discusses her concerns for her personal safety and is worried about becoming infected with TB:

We have XDR⁴³ patients and they are sent back to the community ... It's scary. I mean you have to be careful of yourself. You don't spend more time indoors. Rather you say "Oh what a lovely day. Let's sit outside." You have to be diplomatic ... You know very well that you can't offend her but you are also protecting yourself ... Hospice say "OK we have given you a mask," but it doesn't mean that by wearing a mask you are 100% safe. (J 849-851) (J 853-854) (J 875-878)

People who are infected with a specific type of TB (XDR TB) are discharged from a healthcare institution into the community. Jabu is aware of the risk of spread of such disease at home. In a hospital context a healthcare professional may have access to more protection as medical wards may be well ventilated and masks may be available to prevent the spread of disease. It may be more common, acceptable or even compulsory to wear a mask in a hospital setting. In a home the nurse is vulnerable to TB and other diseases, and as such ability to offer care may be hindered. The issue of personal protection was not raised in the palliative care curriculum.

⁴³ XDR -TB: "Extensively drug-resistant tuberculosis" which is form of TB caused by bacteria that are resistant to the most effective anti-TB drugs. This type of TB can spread from one person to another and may not be amenable to any form of treatment. In KwaZulu-Natal XDR-TB is more prevalent than elsewhere in the world and is extremely difficult to treat; many people who have XDR-TB die from the disease despite intensive medical intervention. The infected person must remain in hospital for many months and the disease can readily be transmitted from one person to another.

9.2.9 Not meeting expectations

Patients live in isolated areas and travel long distances to hospitals. The form of public transport is a minibus taxi which is driven along dirt roads. The taxi may be overcrowded and may not be roadworthy. A patient would be pleased to arrive at a hospital as they have experienced a long, difficult journey in a crowded taxi:

It seems to me that the patient is very happy to see a hospital and when there is a nurse there the patient is going to get help. (J 250-251)

Care in the patient's home focuses on palliative care and care in a hospital focuses on curative care. A patient who has experienced hospital care may be familiar with a concept of curative care. A patient may be less familiar with a concept of palliative care, and when a nurse arrives at their home they may expect her to offer curative care similar to care they have received in a hospital. Nurses must explain that they do not offer curative care:

You tell them - there's nothing, it's just palliative. You're going to do address the palliative issues and you are not going to get that person healed. (T138-142)

At home a nurse enters into a patient's space and she is unsure of the expectations of the family. The home space becomes inhabited by a caregiver and she is acting alone without support. At a hospital there is a building, medications, equipment and healthcare professionals and a patient expects to be cured of illness. The patient's expectations may not be met at home and palliative care may be viewed as less than curative care - "there's nothing, it's just palliative". Patients' views on palliative care and curative care may have a profound effect on how palliative care is practiced. This issue was not raised in the palliative care curriculum.

9.2.10 Invisible care

In a hospital a nurse will have specific duties, such as changing dressings, administering medication and bathing patients. Other members of the healthcare team have other specific duties; for example, a social worker will examine a patient's financial situation and will support them in accessing Government income support grants if required. At home the type of care offered by a nurse is different to that offered in a hospital, and a nurse can offer what is traditionally regarded as social work care. In a hospital a nurse can be seen with equipment such as stethoscopes, barometers and thermometers, and at home she may not have any equipment. At home she talks and listens, and the patient may not value this type of care as an intervention. The care is perceived to be "invisible care", and in several instances nurses found it challenging to provide invisible care:

I can't help because I have nothing. (J 251)

It is hard to explain this to the family as when they see a nurse coming to the house they expect that nurse must do miracles and do wonders and heal this person ... Yet you tell them - I can't help because I have nothing. (T 142-143).

Home care may be challenging as patients and nurses may expect the nurse to carry out the same role as she would in a hospital, and a palliative care curriculum may need to address such potential challenges which occur in practice.

9.3 Hospital care

Caregivers discussed little around hospital care, and this may reflect that they work in a home care context. Jabu describes that hospital care may be of benefit in palliative care:

It seems to me that the patient is very happy to see a hospital and when there is a nurse there the patient is going to get help (J 250-251).

In a hospital a patient would have access to medication, equipment and health care professionals which are not be available in a home context. Hospital and medical care are not without challenges, as I illustrate a few challenges described by caregivers.

9.3.1 Withholding care

As illustrated by several caregivers, when medical care is required it may not be available as it may be withheld by doctors, nurses and pharmacists:

Morphine! Doctors are reluctant to prescribe morphine to our patients ... they are very, very reluctant to put the patient on to morphine and you've got to explain and explain and explain until they are convinced that the patient is really needed to be started on morphine. Doctors believe that morphine enhances the death of a patient, meanwhile the patient is suffering, having severe pains and there's absolutely little that you can do to help that particular patient. (T444-447)

Thandeka feels that medical care is required in the form of analgesia, and in her opinion doctors may withhold a potent analgesia from patients. A view of caregivers is that medical care focuses on prolonging life while their care focuses on alleviation of suffering. Two oppositional views are presented, and in caregivers' views reasons for a doctor's withholding of medication are not acceptable. A doctor may not have had any training in palliative care or may not agree with concepts underpinning palliative care. Some doctors feel that they must do all in their power to prolong the life of a patient and may regard palliative care as opting out or giving up hope. They would not offer any medication which they feel would directly cause death. In another instance, Jabu illustrates that medical care may be withheld by a nurse:

I go to a clinic with the patients card⁴⁴ and I say to the nurse - so and so has pain. The nurse asks, "Where is the patient? Why didn't you bring the patient here?" ... The sisters at the clinic they say, "No, you must bring the patient." ... They don't believe you sometimes. They think you are exaggerating. Yet the nurses are human beings. They treat the patient as a specimen, which is not right. (J 624-625) (J757-758) (J778-781)

Jabu, using her medical experience, discusses a patient with a nursing colleague who works within a clinic context. The clinic nurse does not appear to value the home nurse's experience and withholds care. Jabu feels rejected and not treated as a trustworthy source of information. In a medical or nursing context healthcare professionals generally wish to review a patient themselves and satisfy themselves that they offer the best care available. A clinic nurse doubts the diagnosis of an HBC nurse as the clinic nurse is aware of the limitations of HBC. In the absence of the patient, can the clinic nurse satisfy herself that she offers the best type of care available? Lungi describes that pharmacists may also withhold medical care:

You need to get pharmaceutical training before you handle all the medicines, so amongst us older generation we don't have that because the younger ones that are working in the clinics, I think they do have it. You need to have a pharmacist who can check all your medicines. With us we've got the skills but not the - what can I say - authority. (L291-294)

Her discussion speaks of experiential learning⁴⁵ and credentialed knowing.⁴⁶ Despite not having specific "credentialed" training, Lungi believes she has experience and knowledge of medicines, "we've got the skills". She ascribes a relatively higher importance to experiential learning than credentialed knowing. The study of pharmacy is complex as many aspects of medications need to be known. The pharmacist must be aware of the dose of the drug, frequency and route of administration, side-effects and interactions. New medications are continually being developed and a pharmacist must keep abreast of these. Experiential learning cannot be assumed to be of more value than credentialed knowing.

⁴⁴ The patients' card is a system of hand-held medical records when the patient keeps the medical records and not the healthcare institution. The clinic would have no record of the patient.

⁴⁵ Experiential learning is the process of making meaning from direct experience. Aristotle once said, "For the things we have to learn before we can do them, we learn by doing them."

⁴⁶ By credentialed knowing I mean an overemphasis on diplomas or degrees in deciding what a person can or cannot do.

The curriculum was certain that hospital care would act as a back-up for home care, and data indicate that this is not certain in practice.

9.3.2 Impersonal care

In a hospital setting there is generally a chain of communication in that a doctor will usually make decisions on a ward round. The doctor will convey these decisions to a nurse who will in turn will follow instructions and relay the doctor's decision to a patient and their family. Thandeka describes a situation when she sees this chain of communication as a form of impersonal care:

For the doctors it's easy because that doctor will just write in a piece of paper and then go. It's you who's a nurse now who's going to explain this thing to the very patient and the family that you are not going to do anything now. The doctor will just write and go. (T195-197)

She has a view that a nurse acts only as a messenger between a doctor and a patient, and doctors do not have to face the consequences of their orders. They do not face a patient's questions, hurt and pain. A nurse may have to explain and justify a decision although she is may not be involved in making the decision. Thandeka's discussion alludes to medical care as being used in an authoritarian manner. In a hospital context it may be expected that a doctor behaves in this way, but this nurse construes this as impersonal care.

Nurses work set hours (usually an 8-hour shift) and a nurse will remain on the ward after the doctor has left. They have more time to meet with the patient and their family and may have more time with the patient.

Thandeka's discussion implies that she feels uncomfortable when informing a patient that palliative care is required; however, the patient and their family may be grateful that someone has made this decision known to them: the curriculum advocates that a patient be told "bad news" around the poor prognosis of an illness and Thandeka seems uncertain about this in practice.

9.4 The work of caregivers in context

In analyzing data around the work of caregivers in home-based palliative care, I sought caregivers' descriptions of the work they carry out.

9.4.1 Social work

Lungi discusses her role in acting as a social worker in providing social care to a family:

You can see that the grandmother is old now and stressed out. But we, as palliative care people, need to give a hand just to give the elderly lady a break from looking after her daughter. As we need to give them a break even for two hours, that would be enough. (L 486-491)

In the context of this study, there are many children who are orphaned and the only person available to care for them is an elderly relative. The children may be HIV positive and may require a high degree of care as they have to attend clinic regularly and protect themselves and others from infection. The elderly shoulder the burden of care, and the role of the palliative caregiver here is not in providing medical care. The caregiver may have to provide social care in that she provides the grandmother with the opportunity to take a break.

9.4.2 Pain and symptom management

Several caregivers describe their role in managing pain and other symptoms:

Palliative care is about pain and symptom management. In palliative care we can be experts but we are mainly supporting care for all the patients on all levels because once they leave the hospital they will need somebody who will encourage them to take the medication. (L 310-313)

Lungi believes that the work of palliative care is about pain and symptom management, but in this context her practice may not prioritize pain and symptom management.

In a context of high HIV and TB prevalence, Lungi sees her primary role in psychological care where she must encourage and support patients. Her psychological care involves a practice of “drug policing” in that she regulates and monitors drug taking; patients must take drugs every day. She may have to encourage patients to continue to take their medication as patients may be relatively uneducated about medical treatment protocols; for example, patients may believe that medicines are only needed when a person is sick. In order to be successful, antiretroviral medication must be continued for life and must be taken even if the patient is well. Similarly, treatment for TB must be taken for a prescribed time, and a patient may stop taking the treatment when they begin to feel better.

9.4.3 Cultural work

In the previous chapter caregivers described that traditional beliefs and practices are common and form an important aspect of Zulu society. Jabu highlights the importance of a traditional practice such as animal slaughtering:

I still remember that there is a patient who died at hospice and these African people they wanted to go and slaughter the chicken there. They wanted to call the ancestors and the hospice staff said that they were not allowed to do this ... It is a difficult situation. (J 331-339)

Jabu is aware of the importance of the practice of traditional rituals and of the role of ancestors in society, and sees a role for palliative care as cultural work. In Zulu culture ancestors play a vital role in the lives of the living and can exert influence and guidance. Among the Zulu the belief in ancestral spirits (*amadlozi* or *abaphansi*) has always been strong. Zulu people believe that the spirits of the dead mediate between *uMvelinqangi* (God) and the people on earth. Zulus believe in a long life that continues after death. Jabu alludes to difficulties she experiences in trying to reconcile a role of cultural work within a hospice context. A hospice context may appear to be uncaring; however, the cultural traditions of the “African people” may differ to cultural traditions of non-Zulu people and caregivers at this hospice. Slaughtering a chicken may be offensive to people from other cultures. Caregivers describe aspects of their palliative care training around cultural work:

It [the palliative care course] didn't involve people who are practising traditional medicines. You never invited a Sangoma⁴⁷ there and you never invited an Inyanga⁴⁸ there to tell us what they think we need to do in order to ease the life of the person that is suffering from HIV and AIDS. (T 80-84)

The curriculum was uncertain around cultural issues, and the practice is certain. Thandeka describes that a Sangoma and Inyanga were excluded from palliative care training and implies that they can have a role in cultural aspects of palliative care, "easing the life of the patient." Thandeka suggests that Sangomas and inyangas are of particular relevance in palliative care as they can know more about the problem than just the physical aspect of the problem:

I believe that it would have worked because they will come with their own understanding of the whole problem because some of the problems are not really physical. The problem is psychological so if you address the issue of the mind sometimes the person gets relief. (T 86-88)

Thandeka advocates for the inclusion of traditional healers in training. Their training took place in an urban space and traditional healers may not be readily available to visit a training centre. Traditional healers may require finances for transport, accommodation and sustenance if they have to travel long distances, and this may prove to be expensive.

9.4.4 Spiritual work

Caregivers describe their role in spiritual work:

We educate people that if you are dying you should try and make every wish successful. Sometimes people love to go to the church and sit next to the sick person and read the Bible and maybe sing a song. (N 265-269)

They encourage people to attend church. Caregivers discuss their own beliefs around palliative care and dying:

⁴⁷ A Sangoma is a practitioner of herbal medicine, divination and counselling in traditional Nguni (Zulu, Xhosa, Ndebele and Swazi) societies of Southern Africa. A Sangoma is called on to communicate with ancestral spirits.

⁴⁸ An Inyanga is an herbalist who is concerned with making medicines from plants and animals.

Palliative care, it's the last stage of life; you know when the person is very, very sick. He sees a dead person and everything. The patient sees someone and there is no one there, like he is dreaming. People are calling to him... Like my father is dead and when I am sick my father will call me. I will tell people that my father is calling me and I am sick and anyone can see that I can go anytime. (N 393-397)

Nhlanhla (an HBC worker) alludes to the role of the ancestors in spiritual care. Caregivers describe aspects of their palliative care training around spiritual care:

They did invite pastors of a Western kind of religion. They never involved African religious leaders ... There is a great number of our African people who now go to Shembe religion because it allows them to practice their own Africa cultures like slaughtering, like wearing traditional attire, like having polygamy and using traditional medicines. (T 100-101) (T 109-117)

Thandeka alludes to hegemony of Christianity (a Western kind of religion) in her palliative care curriculum experience. She specifies that African religious leaders were excluded in her curriculum experience; as such, the curriculum seems uncertain about religions in this rural context and the practice seems certain. It may be that there are people who practice other religions in the context of this study, for example Hindus, Muslims and Jewish people who live in rural areas close to the study site.

9.4.5 Communication work

Caregivers describe that they see communicating with patients as part of their work. As an example, Phumile (an HBC worker) portrays a caregiver's work in communication information about approaching death. She illustrates difficulties in carrying out this work:

Traditionally in our culture if you talk about death it means that you have come to predict death, that death will come soon to this family. I remember my first family I went to introduce myself and I felt I was not accepted. I was chased away as one family member said to me, "You have come to predict that someone in this family is going to die. So please, we are not interested. We are no longer interested in listening to your stories. Now go away." (P 100-109)

She depicts how she attempted to enter into a house and was shunned. From a family perspective her communication may be incongruent with their private, traditional ways of caring and her discussion around death may have offended them. From a cultural perspective, it may be inappropriate to communicate information round dying.

9.4.6 Psychosocial and physical work

Caregivers described many roles and described that they sometimes must carry out different types of work for one patient:

We address the psychosocial issues, and we address the physical problems. You will find that the person will be presenting with headaches, rashes, neuropathy,⁴⁹ diarrhoea and TB. All of these symptoms are in one person. (T62-67)

Caregivers carry out physical work as they bathe patients and dress wounds. They diagnose physical problems and offer what analgesia they have available. They refer to clinics for medication. They carry out psychological work as they offer ongoing support around taking medication. In caring spiritually, they discuss death and encourage patients to attend church (caregivers did not state which church, and it would be important to know which church patients were encouraged to attend). They experience some challenges in meeting multiple roles, as patients experience a myriad of problems and caregivers can be unsure of what the patient needs most.

⁴⁹ Neuropathy refers to pain in nerves due to damage of the nerves. The nerves may be damaged by HIV itself or by medication used to control HIV.

9.5 Palliative care in context

When scrutinizing data around caregivers' conceptions of palliative care in their context, I analyzed whether palliative care is a new idea or an old idea in this context. I searched for data which pointed towards whether palliative care is or should be specialized care provided by experts. I also looked for data which considered if palliative care practice requires a scientific evidence base, as I wished to allude whether caregivers' data revealed hegemony of positivist ideas. I first discuss that caregivers were not sure whether palliative care was a new idea or not. Secondly I discuss whether caregivers saw palliative care as a new idea and/or as specialized or expert care which needed a scientific evidence base.

9.5.1 An old idea masquerading as a new idea

In some instances, caregivers felt that palliative care was an old idea masquerading as a new idea:

In my opinion, palliative care is just a fancy name given to something that we, as nursing sisters, have always done. Because I mean all these years people have been doing this thing without giving it a name and then somebody is just fancy and then give it that name. (J265-268)

Jabu suggests that palliative care is not a new concept in Africa and nurses have been practicing palliative care without naming it as such. The term palliative care was coined by someone who wanted to appear "fancier" to other people and perhaps wished to signal that this type of care is new and unique:

But I ask you what is palliative? It's what the people have been giving only they didn't have the collective word for all what they doing. We have been caring for very ill and dying patients for all these years and the only thing they didn't do is give it a name. The nursing sisters have just been carrying on with the clinical part of it. The social workers have been doing all this social work about the patient. The patient's needs have been just attended to without this fancy word. (J 268-275)

Jabu sees palliative care as not a unique or new way of caring and questions if the way of caring is not new then why is there a new name. She believes that palliative care, as an old idea, was already practised by nurses and social workers. Jabu is a nurse who has experienced caring for patients who have an incurable illness and who may face death. Less experienced healthcare professionals may not have shared similar experiences and may not have cared for patients who cannot be cured. Caregivers may have only been exposed to specific work, such as a social worker accessing grants, and may not be aware of all that palliative care offers. For less experienced caregivers palliative care may represent a new idea.

9.5.2 A new idea for bereavement care

Several caregivers viewed palliative care as a new idea and expressed that this new idea could be of benefit to them in several ways. In particular, palliative care as a new idea focused on bereavement care:

What I think has been happening is that the nurses have just been looking after the patient and then when the patient has died the nurses sent the family home. Once the patient is gone the nurses say goodbye without attending to the grief, bereavement period. Before palliative care they used to neglect or they were not aware that more harm is done when the patient is gone. (J 279-281)

Prior to introduction of an idea of palliative care, a nurse focused on care of the dying patient which largely excluded care of the family - and care ceased abruptly when the patient died. Jabu believes that nurses did not recognize that the family was particularly vulnerable after their loved one had died and required ongoing support. Bereavement support should therefore form an essential component of care: palliative care encompasses care of the dying and the living.

All of a sudden you don't just wean the people. You just don't abruptly stop your caring as the family is so used to you and now they are in a very vulnerable situation. They are grieving but the people at the hospital are not there, so that's why the palliative has really improved on that side that the bereavement is also included now. (J 281-286)

Jabu feels empathy towards families and is sensitive to the vulnerability of a grieving family. There are dangers associated with an abrupt withdrawal of support and from a medical perspective dangers could include depression, suicidal thoughts, loneliness, anger and feelings of abandonment.

Zanele discusses her personal experience of the usefulness of a new idea of palliative care and bereavement:

The palliative care helped me deal with the death of my father. I wasn't able to go through painful memories but since I did the palliative care everything is fine. I can talk to other people about deaths that I have experienced and before I wasn't able to talk. It is time to grieve now because someone has explained to me about dying and everything. (Z367-371)

Palliative care was useful to her for personal reasons as in the absence of palliative care she did not receive bereavement support. Palliative care facilitated opportunities for her to discuss her experiences and gain knowledge about issues around dying and bereavement. She can see the benefits of palliative care for people, like her, who have lost loved ones.

9.5.3 A new understanding of a medical decision

Caregivers implied that palliative care is of benefit to them as it facilitates their understanding of decisions made around withholding active medical intervention in a hospital context:

Before palliative care I wasn't able to understand why the doctor is saying there is nothing we can do to this person. (T187-188)

Thandeka implies that palliative care enabled her to make sense of a doctor's decision around care. For example, before her palliative care training she may have regarded a doctor saying "there is nothing we can do" as uncaring and defeatist. After palliative care training she may be able to make differing sense of such a decision.

9.5.4 A new approach to preparing for death

Several caregivers implied that palliative care is a new and useful idea in preparing patients for death. They discussed that palliative care enabled a patient to make preparations such as leaving mementos, gathering together official documents, realizing long-cherished dreams, attending church and communicating with “long lost” relatives.

Zanele and Sindiwe (an HBC worker) discussed that it is useful for people to know that their own death is near:

It is fair that people know that they will die soon. Sometimes we are hiding things that they have not been exposed to. ... We were just following in the elders' ways. (Z133-138)

Everybody has the right to know what is happening in the world and they have to make decisions. Even the children have to make decisions in a family. When a person dies and they are in mourning, they have to know why we are mourning today. (S 633-636)

Palliative care differs from traditional elders' ways of caring for the dying, when prior to palliative care there was a “conspiracy of silence” and hiding of information around dying and death. Sindiwe advocates that patients should be aware of their approaching death as it is a patient's right to have knowledge on this issue. Both these caregivers are not healthcare professionals and their conversations emphasize a need for professional support in this context, since telling a person that their death approaches requires a high degree of support and certainty around prognosis; an unsupported, unsupervised, inexperienced caregiver could make a mistake and inform a patient that they are dying when they are not. A patient may be traumatized unnecessarily or may be denied access to potentially curative interventions. A patient may lose faith in the caregiver if they are told that they will die soon and do not die. A patient may give up on life and abandon all hope if they are told that they will not live.

In another instance, Nhlanhla discusses that it is useful to prepare for death:

OK. If you are looking after a sick child you must love them and you tell the family that they must organize a memory⁵⁰ box. If these children die, the family can look after the photos and birth certificate and marriage certificate for their parents. We educate people that if you are dying you should try and make every wish successful. Sometimes people love to go to the church and sit next to the sick person and read the Bible and maybe sing a song. (N 265-269)

Earlier I discussed which church caregivers encourage patients to attend, and these data suggest that patients attend a Christian church. This provides somewhat oppositional data to Thandeka, who suggests that traditional African churches (such as Shembe) are important in this context. Palliative care is seen to be useful as it advocates for collection of mementoes of the dying and bereaved. Nhlanhla also alludes to the importance of storing official documentation for future use and the benefits to the bereaved in having something tangible by which to remember the deceased. In another instance, Sindiwe suggests that an idea of palliative care is of benefit as it facilitates discussion around who will accept the deceased person's responsibilities and possessions:

Palliative care it does change things. When we are dealing with a person who is dying some other people are worried. Who will take care of the children? Who will be responsible for the house? ... Palliative care teaches you a lot. You can see when you are facing death you can make a will. You can leave your house to someone. You can find your relatives and say whatever you want to say to them. These people will remember you, they will remember that you said we must do this or that and they will be grateful and happy. (S 611-622)

It is beneficial to make preparations so the dying can articulate their decisions around their family and home to relatives. Sindiwe's discussion may also speak of importance that the dying attach to concern that they be forgotten after their death, "the people will remember you."

⁵⁰ A memory box is a box provided by some hospitals, clinics and home-care organizations. It may be made by those who expect to die soon or expect to be bereaved. The box contains objects belonging to or representing the deceased person and is used to help relatives deal with grief and plan for the future.

Dorcas (an HBC worker) suggests that a benefit of palliative care is that there is an opportunity to prepare for the death of a parent. In her context there are many orphans who have lost their parents to HIV disease, and in her opinion children should see death as a final event and move on with the rest of their life:

The children didn't even get chance to say goodbye but I speak to them. I give them that chance. Some children write a letter, some go to the graves. They are starting their life better now. They must know that they must start afresh and get used to new people. Forget about the past. (D 356-361)

Her discussion infers a cultural tendency to shield children from the reality of death. Her opinions may seem harsh and uncaring to an outsider in that she advocates that orphans are told about the death of their parents and are instructed to “forget about the past, start afresh and get used to new people.” However, in her context this course of action may be necessary as there are many orphans and few facilities available for their care. Orphans must focus their energies on surviving and on the future.

9.5.5 Experts in physical care

In some instances caregivers see themselves as experts in providing aspects of care and specifically mentioned pain and symptom care:

Palliative care is about pain and symptom management. In palliative care we can be experts but we are mainly supporting care for all the patients on all levels, because once they leave the hospital they will need somebody who will encourage them to take the medication. (L 310-313)

Lungi implies that an espoused role in palliative care theory is development of expertise in pain and symptom control, and she describes that her work includes a role other than just pain and symptom control; for example, she must offer psychological support to encourage people to keep taking medication.

9.5.6 Expert in theory and not in practice

Several caregivers described instances when they felt that they were experts in palliative care theory but could not apply their expertise to practice:

I don't think we are doing palliative care as such here in South Africa. For instance, they said we must practice holistic care and I wonder from both patient and nursing conception how to do this. I am a palliative trained sister and I go and see a patient because the patient has got a lot of pain and I say to the patient, "Go back to the ARV [antiretroviral] clinic and tell the doctor that you have got painful feet." ... I am a palliative sister, we are now not allowed to get in and carry any medication or anything and what am I going to do then, rubbing the feet? (J 246-248) (J 228- 234)

Jabu challenges some of the assumptions and philosophical underpinnings of palliative care theory. As an example, she alludes to theory that a palliative caregiver should be an expert in "*holistic*" care and implies that in context it is not possible to offer such expertise due to a lack of resources. Some of the concepts associated with palliative care are not achievable in practice:

It does make me angry that I am helpless because there is nothing I can do about it. I mean no one is listening to this. For example, they say "OK palliative care. You have been taught to palliative care. You have been taught to do 1, 2 and 3."... Why can't they just give us that power of those instruments? It is just like somebody said "Now you have been taught to chop the wood and everything is OK." They say "there is a pile of wood there now go and chop it." They don't give you an axe. (J 421-424) (J 426-428)

Jabu is upset as in her view she has been taught a theory but is powerless to enact that theory in practice. Management of her organization takes it for granted that theory can be enacted and yet it cannot be enacted as she does not have necessary tools. She alludes to tensions between being an expert in theory and not being able to be an expert in practice, and she experiences anger at this situation which is fuelled by her perceived powerlessness.

In a second instance, Lungi also alludes to feeling upset because in her view she cannot put her theoretical expertise into practice:

It makes me feel bad because I really need the pain tablets to do palliative care as it is about pain control and I can't even give a Panado⁵¹ tablet which can be found on the shelves in the supermarket and it's not even expensive, I think it's about 10 rand⁵² for 10 tablets. (L287-289)

Lungi suggests that she cannot enact palliative care theory around pain control as she cannot give a readily available analgesic medication to a patient who has pain. In another instance Thandeka alludes to not being able to apply her expertise to practice:

I believe that the course content was enough although sometimes the exposure was inadequate. The course was mainly on cancer, there was little that was done on HIV or AIDS, and meanwhile we here are concentrating on HIV and AIDS. The course was more relevant for people that are dealing with palliative care for people with cancer. (T57-60)

Thandeka suggests that theory placed an emphasis on palliative care for people who had cancer, and this emphasis did not reflect the reality of her daily practice as most patients in her context have HIV and not cancer. She intimates that theory assumes that palliative care for people who have cancer is similar to palliative care for people who have HIV disease, "one size fits all." In Thandeka's perspective there is a clear distinction between palliative care required for people who have cancer and palliative care for people who have HIV, "one size cannot fit all":

I think maybe we need to put in more information on HIV and AIDS to make the course more relevant to us ... The problems faced by people with HIV and AIDS are different to the problems faced by people who have cancer ... In cancer it's maybe a sore and meanwhile here with HIV disease and AIDS we deal with a cluster of symptoms. We address the psychosocial issues, and we address the physical problems. You will find that the person will be presenting with headaches, rashes, neuropathy,⁵³ diarrhoea and TB. All of these symptoms are in one person. You end up not knowing which one to start with. (T62-67)(T 67-73)

⁵¹ Panado is a local name for paracetamol.

⁵² Rands are South African currency

⁵³ Neuropathy refers to pain in nerves due to damage of the nerves. The nerves may be damaged by HIV itself or by ART used to control HIV.

People who have both cancer and HIV experience the symptoms described by Thandeka (headaches, rashes, neuropathy and diarrhoea), and it may be that curriculum provided for both care of HIV, AIDS and cancer (one size can fit all). In opposition to Thandeka's view that palliative care can be offered as "one size cannot fit all", some may advocate that the principles underpinning palliative care can be translated from one disease to another.

In context this caregiver finds it challenging to decide which problem to deal with first, as the patient may have many problems requiring her attention. Palliative care curriculum did not provide any guidance on triaging⁵⁴ problems (determining which problem requires immediate attention).

9.5.7 A lack of expertise

Palliative care theory advocates that a caregiver should explore whether a patient wishes to be given information around their impending death. Caregivers revealed that they were not always experts in carrying out this role:

I try to be positive because I can't tell straight. If I see this thing is wrong I can't tell the patient that you will die. I can't tell the patient I can't help you. I can always help. (Z 326-327)

Zanele appears not to consider herself as an expert in breaking bad news to a patient. She experiences challenges in disclosing information about futility of curative intervention - "I try to be positive." She experiences challenges in disclosing to the patient that they face death "I can't tell you straight". She may regard palliative care as an opting out sort of care and cannot reconcile this with her way of caring - "I can always help." This presents a dichotomy as Zanele sees telling about death as not helping and conversely not telling about death as helping. Palliative care curriculum advocates certainty that telling about death can be helpful, and in practice caregivers seemed less certain about this issue.

⁵⁴ In using the word triage, I refer to a process for sorting out problems and injured people into groups based on their need and on a rationalization around what or who is most likely to benefit from immediate medical treatment.

9.5.8 Abuse of expertise

Caregivers allude to challenges when healthcare professionals appeared to abuse the expertise associated with palliative care:

This is now palliative care. It's very, very hard especially when the doctors just look at the patient with their eyes from the end of the bed and say go home now it's palliative. I've seen letters coming from doctors that patient is being discharged for palliative care and it's hard to explain to a person who is really dying that the doctor has sent them away. (T136-138)

This caregiver implies that some doctors may see palliative care as only being offered by experts who work in patients' homes. They may label a form of care, in which they have no perceived involvement, as palliative care. Palliative care is offered only by experts in palliative care and therefore there is no point, as a non-expert, in trying to care. Some may abuse this perception to justify their poor treatment of patients - "look at the patient with their eyes from the end of the bed." A doctor should thoroughly examine and treat a patient even though the doctor may perceive this action to be futile in saving the life of the patient. The doctor may feel that a patient wants to go home and that nurse at home is best suited to offer palliative care. The doctor may feel that the home is a better place to break bad news than a busy medical ward, and the caregiver sees the doctor as shirking responsibility.

9.5.9 Scientific evidence-based practice

Working within a realm of specialization and expertise, palliative care curriculum advocated for scientific evidence on which to base practice and caregivers discuss that scientific evidence is not always of use to them in practice:

It is not scientifically proven and it is not tested in laboratories but traditional healers do work as most of the time as it is about faith. If you believe in something that is going to help you then it does help you even if it wasn't designed to care for the illness that you are having. The mere fact that you believe that it is going to work will help you. (T 92-96)

Thandeka's discussion may allude to hegemony of medical science in palliative care and its associated requirement for "scientific proof": palliative care will not accept a practice if there is no scientific proof that the practice works.

Doctors and nurses have a large burden of responsibility in that the lives of patients lie in their hands. They want to make sure that they are doing the best that they can, and science offers a way of knowing about medications, scans, tests and operations. However, some things may not be provable; for example, a miraculous cure cannot be explained by science. Thandeka may allude to a placebo effect and she presents science and faith as dichotomies. A palliative care curriculum may need to take cognizance of this and not present science and faith as dichotomous issues.

9.6 Conclusion

This chapter presents data for study question three, which is concerned with caregivers' experiences of palliative care practice. These data fell into four themes: home care, hospital care, work of caring and palliative care.

Most data were presented by nurses. Caregivers discussed a context of place of care and HBC at length, and there were notably less data on medical or hospital care. Within a theme of home care, caregivers implied that care should be provided irrespective of a diagnosis of a life-limiting illness as it was difficult to know who had a life-limiting illness or not. Home care was beneficial as patients could have increased access to care. Caregivers and patients could become humanized as caregivers could develop a deep, caring relationship with their patient and were appreciated by patients and families. Seeing the patient in context as a "human" beyond their patient identity was seen as important, and home care specifically is of more benefit than hospital or clinic care in allowing such caring. Home care is in keeping with age-old traditions in Africa around community involvement and support in day-to-day life. In particular, home care is of benefit when people wish to practice traditional customs or make use of traditional medicines. Home care enabled caregivers to independently implement knowledge, and such an independent type of caring is important when there are no senior professionals readily available for advice and support.

However, home care can also be challenging as, for example, patients did not always appear to value this type of care offered in a palliative care intervention. Home care could pose dangers for caregivers and did not always meet the expectations of patients. Interventions such as analgesia were not available. Hospital care was regarded as beneficial as a patient would have access to equipment and medications. However, hospital support could not always be depended on and medical care presented its own challenges, including withholding care and impersonal care.

Caregivers described multiple roles, which included pain and symptom control, social, spiritual and cultural care. They illustrated profound challenges in meeting some of their multiple roles.

Some saw palliative care as a new idea and others saw it as representing nothing new. Palliative care offered new ways of bereavement care and preparing for death, and offered new ways of understanding medical decisions.

Caregivers described themselves as experts in some aspects of care and experienced challenges in translating their expertise into practice. Expertise could be abused, and an evidence base for palliative care was not seen as always necessary for practice.

In the following chapter I juxtapose the data with the literature in order to deepen understanding of curriculum and caregivers' experiences.

CHAPTER TEN

Palliative care curriculum and practice

10.1 Introduction

In chapter nine I explored the experiences of caregivers who had been exposed to a palliative care curriculum (espoused) and I related their experiences to an enacted curriculum. In this chapter in order to broaden and deepen understanding of data, I stick close to the themes which arose from data and relate these themes to published literature. I remind the reader that the data was themed using a “bottom-up approach” which does not involve fitting data into predetermined themes (a top-down approach). In inducing themes the researcher looks at the material and tries to work out organizing themes which “naturally” underlie the material.” I open the chapter with a general overview of the nurses’ palliative care curriculum and follow this with a discussion around four themes: an overview of the palliative care curriculum, place of caring, the roles of caregivers and palliative care as expert care. Each theme is divided into sub-themes, and to orientate the reader I provide an overview of themes and sub-themes in Table 7.

Themes	Sub-themes
An overview of palliative care curriculum	<ul style="list-style-type: none">• Diametric worldviews• An old curriculum in a new context• The cared for
Place of care	<ul style="list-style-type: none">• Home care• Hospital care
Roles of caregivers	<ul style="list-style-type: none">• Cancer care• Poverty care• Spiritual and cultural care• Communication work: Troubled by speech, disturbing the silence• Ambiguous roles, definite roles
Palliative care	<ul style="list-style-type: none">• Experts on theory and not in practice• Expertise as power• Evidence-based practice

Table 7: Summary of themes and sub-themes in palliative care curriculum and practice

10.2 An overview of the palliative care curriculum

I find it noteworthy that caregivers referred little to the curriculum or to their training in palliative care. These nurses had been exposed to a practice of caring for the dying and bereaved prior to their palliative care training, and it may be that their prior experiences of caring rather than curriculum form a potent driver in their practice of palliative care. In this section I bring together dimensions of the nurses' palliative care curriculum into dialogue with the literature and hone in on three issues: diametric world views of the teacher and learner, palliative care curriculum within a palliative care-naïve context, and the cared for. I discuss each of these three themes in turn.

10.2.1 Diametric worldviews

The curriculum was presented to Zulu women by a white woman, each group holding diametric worldviews.⁵⁵ As an example of teachers' worldviews differing from those of learners, consider studies in English literature which found that teachers who teach learners from a culture other than their own may not be aware that strategies they use to teach may act to marginalize learners (Mohammadzadeh, 2009). European teachers used traditional Eurocentric teaching strategies, and as a result these teachers were not able to encourage their learners to critically review representations of their own and other cultural groups encountered in literary texts. Mohammadzadeh (2009, p. 25) recommended that teachers employ methods such as postcolonial literary theory,⁵⁶ to enable both them and their students to understand more effectively the worldviews of dominant and subaltern cultures found in both Eurocentric and postcolonial literary texts. In a critical paradigm postcolonial theory is important; however, I do not consider postcolonial theory here as the study is more focused on a general situation where a curriculum is introduced into a context other than its context of origin.

⁵⁵ By worldview, I refer to a particular philosophy of life or conception of the world. A worldview is the fundamental cognitive orientation of an individual or society.

⁵⁶ The ultimate goal of post-colonialism literary theory is accounting for and combating the residual effects of colonialism on cultures. It is not simply concerned with salvaging past worlds, but focuses on learning how the world can move beyond this period together, towards a place of mutual respect.

A worldview is a complex notion and is not dependent only on a single factor such as race. For example, a woman who trained as a palliative care nurse in Europe may have a differing worldview to those she teaches elsewhere in the world. A worldview may be influenced by many factors, including race, gender, culture, class and training. For example, if a nurse is HIV positive then she may feel empathy towards her patients. Findings from this study illustrated several worldviews and I present three: language, place and palliative care as a team.

Firstly, as an example of diametric worldviews in language, the palliative care curriculum notes that the medium of instruction is English - the second language of caregivers. Caregivers noted that they did not do as well as they expected in their examinations and felt that their examination required them to write a lot. A disappointment in their results could reflect that they were writing in a second language. Literature describes that 90% of the population in Africa speak only African languages, and purports that language is not only a tool for communication and knowledge transmission but is also fundamental to cultural identity and empowerment (Phillipson, 1995). Promoting African languages, described as official languages, is necessary *“to mount a sustained campaign of educating or re-educating the national population about the inherent or potential practical utility of African languages and to counter the present widespread negative attitudes in Africa towards these languages”* (Phillipson 1995, p. 162).

A challenge for any education system may lie in the reality of developing a curriculum when there are many languages (South Africa has 11 official languages!). A difficulty of producing a curriculum in a situation where there are many languages is illustrated in Europe: in 1997, the European Association for Palliative Care (EAPC) proposed that minimal recommendations and standardized outcomes for palliative care training and evaluation for both doctors and nurses be identified (de Vlieger *et al.*, 2004). The EAPC has tried to unify the European voice of palliative care education through its initiative ‘One Voice, One Vision’. Despite the EPCA’s intention to unify palliative care curriculum, difficulties in producing standardized outcomes in palliative care education were noted due to multiple languages in context:

In Ireland for example the proliferation of hospices offering essentially the same course led to some agreements about what should take place, why, where and when. In a small country such as the Republic of Ireland such national initiatives are possible. Compare the example of Switzerland with three official languages and the need for simultaneous translation in triplicate. (de Vlieger *et al.*, 2004, p. 401)

The European palliative care curriculum appears to have experienced problems in finding “one voice and one vision”, and it may do so because not everyone speaks a similar language. In this study a caregiver uses a Zulu word, *Ukumakekela*, to describe how she sees care. This word appears to translate as “care for all”, and palliative care does not appear to have a corresponding word for this concept of care. Worldviews, values and social expectations are so ingrained in languages as to be unquestioned, and may be alien to those from different backgrounds (Crawley, Marshall, Lo & Koeing, 2002).

Secondly, I consider place and worldview as caregivers were trained in an urban context and practiced in a rural context. Their training within an urban space may have attuned caregivers’ imaginations to an urban space for practice of palliative care, and in such a space hospitals, clinics and hospices may be available in which to practice palliative care. Doctors and other colleagues may be available for support. In an urban setting it may be difficult to imagine some of the dangers associated with a rural area, such as hijacking and being blamed for a death.

When caregivers return from their training they may be faced with a situation they have not encountered during their training; for example, they may be chased away when trying to break bad news. They may find that they must try and practice what they have been taught in the absence of hospitals, clinics or hospices. They may have to face patients that are stigmatized, ostracized and abandoned in dilapidated shacks. Practicing in a rural area may require different sets of knowledge and skills and competencies to their urban counterparts. They may have to assume the role of a doctor; for example, caregivers felt that patients’ pain was so severe that morphine was required.

Caregivers had to determine type of pain (such as neuropathic), and in another context a doctor would be expected to differentiate between differing pain types. In a rural context a nurse may have to be more than a nurse, she may have to be a doctor because no doctor is available.

Palliative care education has been criticized for delivery of training at a point other than the point of practice. Linder, Blais, Endres, Maberg & Myers (1999) reported that palliative care education can be enhanced when it is delivered close to the point of care, as it provides learners with more opportunity to discuss issues relating directly to their context.

A review of physiotherapy students' experiences of palliative care in Great Britain revealed that it was important that learning took place within an arena of practice as students could apply what they had learnt to their own practice in context (Morris & Leonard, 2007). The researchers reported that there has been an increasing emphasis on palliative care education in both campus-based and practice-based settings.

In rural Australia palliative care educators held workshops close to doctor students' place of practice, and the content of a curriculum was modified according to local caseloads as identified by the doctor students (Raymond, Charles, Israel, Read & Treston, 2005). Evaluation of the doctor students' clinical performance revealed significant improvements in confidence regarding palliative care knowledge and skill levels, as well as the management of common palliative care symptoms. This rural intervention was based in doctors' surgeries and was reported to be relatively inexpensive, with reasonable reach and was effective as measured by educational and clinical outcomes. Basing learning opportunities at a point of practice and asking caregivers to identify their own palliative care training needs may enable caregivers to closely reflect on their own practice, which is considered to be a major part of the learning process for nursing practice (Hawthorn, 2010). Along with this literature, more recent literature disputes that palliative care training is carried out at the site of practice: Healey (2011, p. 662) writes as follows to the editor of the *Australian Family Physician*:

I have found that the Faculty of Palliative Medicine at the RACP⁵⁷ is very rigid and unyielding in its provision of postgraduate courses. Rather than considering external courses, they want GPs⁵⁸ to go back to a tertiary⁵⁹ palliative care unit. This is not always feasible for established GPs in their practices, particularly in rural areas.

⁵⁷ RACP is the Royal Australian College of Physicians.

⁵⁸ GPs refers to general practitioners.

⁵⁹ A tertiary palliative care unit is a unit based at a hospital with access to sophisticated technological diagnostic, prognostic and treatment tools.

In any context of rural homes caregivers can be geographically isolated, and a lecturer and team may face challenges in reaching learners. It may prove challenging to teach individual caregivers in remote, lonely, inaccessible and potentially dangerous areas.

Thirdly, I consider a worldview of palliative care as a team effort, since the palliative care curriculum advocated that palliative care be offered as part of a “multidisciplinary” or “interdisciplinary team” and that it should be delivered by a group of healthcare professionals such as nurses, doctors and social workers. This view is supported by literature:

Multi-disciplinary palliative care must be responsive, flexible and able to assist at “points of need”, working together with the referring team.

Collaboration across all the medical disciplines and the full health care team is essential and communication between services must be robust so that our care is consistent, unambiguous and patient-centered.

(Grundy, 2007, p. 1)

There is a drive towards teaching palliative care as a team effort, and Hall *et al.* (2005) developed a palliative care seminar course for a group comprising first- and second-year medical students, fourth-year nursing students and graduate students in spiritual care. They noted that this way of teaching enabled the students to transcend their “disciplinary barriers”, and to better understand the perspectives and contributions that other team members bring to patient care. Evaluation of their findings suggested that meaningful inter-professional education can be introduced effectively to students either prior to or while they are maturing in their professional role.

In the context of this study, a nurse taught other nurses, and this may limit learning opportunities as learners may not be provided with the opportunity to be exposed to the worldviews of other healthcare professionals. For example, Thandeka regarded a doctor as uncaring when he signed an order “not to resuscitate” and left her to explain the meaning and implications of the order to the patient and family. A multidisciplinary teaching forum could potentially offer her an avenue to discuss this doctor’s action with other doctors. Doctors could be provided with an opportunity to become exposed to the worldview of a nurse and to hear the concerns of a nurse. Richness around sharing of ideas within multidisciplinary team training could forge the beginning of symbiotic practice which could be rewarding for all members.

The challenges of developing curriculum for a multidisciplinary team are noted in the literature (Chattoo & Atkin, 2009). In particular, aspects of multidisciplinary education and practice often are challenging to realize, as assumptions are made around a shared worldview of healthcare professionals and a *sui generis*⁶⁰ (healthcare professionals may act to protect their own territory). There may be asymmetrical power relationships, which could entrench a superiority of doctors; since doctors generally have more training and status than nurses they may expect everyone to listen to them and respect their point of view. In the context of this study it may be very challenging to offer multidisciplinary training as doctors may simply not be available in either training or practice settings.

10.2.2 A familiar context and a new curriculum

In this study caregivers had been practising a form of care prior to their exposure to a curriculum for palliative care; the context of care was familiar to them. We can compare caregivers' experiences of practising a type of care (a familiar context) before being taught palliative care (a new curriculum) to a situation where teachers had been teaching a form of physical education (a familiar context) before receiving any formal training on physical education (a new curriculum). When physical education teachers moved back from being students to being teachers, they experienced a "reality shock" in which their teaching situations were vastly different from those in their training situations (Veenman, 1984). A reaction to a reality shock was a return to their means of practising teaching which they employed prior to their training. Zeichner and Tabachnick (1981) propose three reasons for this: first, teacher education programmes may have a weak impact on teachers and do not permanently impact their beliefs and practices. Second, while claiming to promote and teach more inventive means of education, teacher education programmes actually support more traditional instructional methods (the training may be similar to the teachers' original practice). Third, the beliefs and skills acquired during the learning process are "washed out" by the circumstances teachers encounter after training. It may be that a prior knowledge and experience of caring in this context was a forceful driver of practice, and issues arising from curriculum and training may be "washed out" in context.

⁶⁰*sui generis* is a noun which means - in its own category, in its own group, of its own character, of its own class, of its own classification, of its own denomination, of its own genre, of its own kind, of its own nature, of its own type, of its own variety, peculiar, special, the only one of its kind, unique.

10.2.3 The cared for

The nurses' palliative care curriculum defines that the patient to be cared for as a patient who has a life-limiting illness. In this study caregivers alluded to a concept of caring for all and did not delineate their caring in terms of a life-limiting illness:

We are giving them all the same care but you cannot identify the ones that are going to die because sometimes you find a very ill patient and miraculously they just recover (L99-100).

Caregivers appeared to work intuitively with some uncertainty around prognosis and diagnosis. Including all people for caring appeared to be culturally sensitive, and using such a concept of caring for all frees the caregivers from having to know whether an illness is life-limiting or not. Within a post-structural stance I explore discourse of palliative care relating to who is cared for in more detail. A post-structuralist theorist would view palliative care discourse as the fixation of meaning within a domain of palliative care. Post-structuralists identify several tools for looking at discourse and I discuss the following: elements, floating signifiers, moments, nodal points and empty signifiers.

Elements are signs that have multiple potential meanings, and as an example of elements consider the term "spiritual care". The curriculum was uncertain around spiritual care and caregivers revealed the importance of spiritual care in practice. Literature notes that conceptualizations of spirituality and spiritual care are in transition in palliative care discourse and some have argued that the concept of spirituality has become so generic that it is no longer meaningful and no one is certain what it means (Pesut, 2008).

Spiritual care could be regarded as an element and elements are signs whose meaning have yet to be fixed, and as such may have multiple potential meanings. Although understanding of spirituality may differ it seems pertinent to carry out research of spirituality within palliative care in Africa to explore different understanding and experiences as a means of shaping a palliative care curriculum.

As a further example of elements, compare the WHO definitions of palliative care and home care. The WHO (1990) definition of palliative care is:

An approach that improves the quality of life of patients and their families facing problems associated with a life-limiting illness, through the prevention and relief of suffering, the early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual.

The WHO definition of home care is:

Any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of community home-based care is to provide hope through high-quality and appropriate care, that helps ill people and families to maintain their independence, and achieve the best possible quality of life. (WHO, 2002, p. 8)

Both palliative care discourse and home care discourse use very similar terms to describe the type of care to be delivered. Palliative care discourse focuses on who gets the care (people with a life-limiting illness), and home care discourse focuses on where the care is provided (at home). Elements common in both definitions are quality care, physical, psychosocial and spiritual. For Laclau and Mouffe (1985) a discourse would try and fix these elements with a meaning, and that meaning can be regarded as privileged. Gathering together privileged meanings creates a “nodal point”, and thus a nodal point in palliative care discourse is a life-threatening illness. Nodal points act to temporally construct and stabilize discourses (Torfing, 1999). Discourse attempts to remove ambiguity and to transform elements into something with a fixed meaning, and this is called a “moment”. The meaning of moments becomes fixed through their differences from each other. For example, palliative care has defined physical care and the moment of physical care differs from the moment of psychosocial care, yet both are interrelated and interdependent. Each moment is fixed by relation to other moments and by exclusion of all other possible moments.

I now relate elements, moments and nodal points to each other. Discourse aims to remove ambiguity by turning elements into moments, but this aim can never be completely successful as the field of discursivity threatens to destabilize the fixity of meaning. All moments are potentially elements. Nodal points depend on moments and are by nature subject to change and transformation. A nodal point could be viewed as “an empty signifier”, which is a term used to denote something that doesn't point to any actual object or agreed upon meaning (Laclau, 2000, p. 185). The descriptor “empty” does not refer to nothingness but rather to a concept that acts as an empty receptacle that can be filled with all kinds of understandings without an anchoring attribute. A floating signifier is something which different discourses struggle to invest with meaning in their own particular way. In practice, empty signifiers can set up a vehicle for hegemonic practice to take hold and fill an absent-fullness to achieve preferred and selective meanings and understandings (Laclau, 2000, p. 185).

As an example of an empty signifier, consider a patient who has TB infection. This disease is caused by a bacteria and anti-TB medication is a set of medications which are available to destroy the bacteria so that a person does not face an untimely death. TB can lead to untimely death if the treatment is not available, if it is taken incorrectly, or if the bacteria become resistant to the medication. TB will only cause certain death if certain circumstances arise. In a rural home a caregiver cannot be sure that a person is taking their medication, and they cannot be sure if the bacteria are resistant to the medication or not, and so they may not be able to say for certain if life is limited by the disease or not. A doctor in a hospital may be more certain as a test or scan can be carried out to check if bacteria are resistant to medication. The doctor may only decide to offer palliative care when the TB disease reaches a specific stage, for example when it becomes multiple-drug resistant TB (MDR-TB). A question arises around TB as a life-limiting illness in the context of rural homes.

If there is no access to diagnosis or treatment then there is an ambiguity around whether TB is a life-limiting illness or not, and a self-limiting illness could be regarded as an empty signifier which can only be filled by a doctor with access to diagnostic, prognostic and treatment interventions. A nodal point of “life-limiting illness” in palliative care discourse could be viewed as illustrating hegemony of medical field as doctors with access to technology decide who has a life-limiting illness and who needs palliative care. There is uncertainty due to contingent operational factors (common in rural Africa) and uncertainty due to inherent/intrinsic factors (will the disease respond to treatment?).

In Southern Africa literature has indicated that it is not doctors but rather ancestors and traditional healer who determine a point when an illness is deemed to be incurable:

Traditional Healers are informed by the ancestors when a patient is dying. They summon and counsel the family of the patient, advising them to take the patient home and to seek no further treatment because God and the ancestral spirits are taking the person who has finished what he came to do in this world ... They ask God and the ancestors to take away the patients' pain and allow him or her to go peacefully. (Hewson, 1998, p. 80)

There may be competing discourses around whether an illness is life-threatening or not and who deems it to be life-limiting. This may seem to be a specious argument as a traditional healer may parallel a caregiver in being uncertain about diagnosis or prognosis, although it does raise an issue of collaboration between palliative caregivers and traditional healers.

According to the WHO definition, palliative care provision becomes dependent on a binary/dichotomy (life-limiting or not life-limiting). In the case of rural African home care, neither part of the binary is totally definable as it may be that we cannot be always certain about what constitutes a life-limiting illness. Binary oppositions have been viewed and criticized as an artefact in Western thought (Derrida, 2004). According to Derrida, language and thought are structured in binary opposition, thus maintaining social hierarchies, and he claims that there is a value hierarchy inherent in them.

Palliative care in rural homes may open to a false dichotomy as a way of thought in which only two alternatives are considered, when in fact there are additional options (sometimes there are shades of grey between the extremes). Discussing palliative care discourse and a nodal point (as a type of patient with a life-limiting illness to be cared for) can be certain in some contexts, whereas in practice in rural homes this meaning becomes embedded within a sphere of constant struggle for meaning. A dichotomy presented by palliative care discourse in delineating care as for those who have a life-limiting illness can become even more confusing when we consider the work of Selman (2007). This author says that palliative care should not only be offered when accurate prognostication is available, and it should be offered simultaneously alongside curative care.

Some advocate that palliative care should not be viewed as a definite shift from wholly curative to wholly palliative, and suggest that we should not wait to see if an illness can be cured or not before offering palliative care; palliative care should merge seamlessly with attempts at cure. Others believe that palliative care should not be offered according to diagnosis or prognosis and rather should be offered according to patient and family need (Chattoo & Aitkin, 2009, p. 149). The authors hold a view of palliative care as a way of care which leads to a focus on dying and not on the living; for example, consider a patient with heart failure - cardiology focuses on 'living with heart failure', and palliative care focuses on 'dying with heart failure' (Chattoo & Aitkin, 2009, p. 149). This is a question of perspectives and generalizes that palliative care focuses on dying.

The Gold Standards Framework in the UK advises three triggers for initiation of palliative care; firstly, palliative care should be offered when a doctor faces 'the surprise question'⁶¹; secondly, palliative care should be offered according to choice or need; and thirdly according to clinical indicators such as cancer, organ failure of elderly/frail and dementia (Gwyther, 2011).

A brief post-structural look at who receives care opens challenges and promotes new ways of thinking for discourses in palliative care. We may need to define conventional notions of palliative care and may need to accept slippage between curative care, palliative care and other types of care as a healthcare worker may work with probability, predictability and unpredictability. Let me expand on what I mean: a patient who has a severe head injury following a motorcycle accident needs care and we may not be sure whether he will recover or not. Curative care may not be possible because the brain may be severely damaged. Palliative care would not conventionally be offered as this patient does not have a life-limiting illness - and so what type of care should we offer? Interestingly, in some centres there is a move away from the use of the term palliative care as both healthcare professionals and patients view this term in a negative light as suggesting dying and death (e.g. Duke University Palliative Care Center use the term quality of life care, rather than palliative care).

⁶¹The Surprise Question refers to - will the doctor be surprised if the patient were to die within the next 6-12 months? If the answer is no, then palliative care should be initiated.

All-inclusive care (as suggested by a notion of quality of life care) as described by caregivers avoids a need to develop a nodal point around a life-limiting illness in a situation where such an illness can become a contentious issue. “All-inclusive care” can act to include much from the excluded “field of discursivity” and avoid promotions of empty signifiers, because all ways of caring for all patients can become included in a discourse of suffering, illness, dying, death and bereavement.

10. 3 Place of care

In this section I first discuss home care, followed by hospital care.

10.3.1 Home care

The espoused palliative care curriculum advocates home care as an ideal space for delivery of palliative care in an African home context. Caregivers implied that, in some respects, home care was a useful place for caring and in other respects it was challenging. It was useful as it enabled humanizing care for the patient, community and caregiver. It represented challenges in the form of dangers and in patients not always valuing care.

Sinclair (2007) provides a critical reflection of palliative care and advocates for home care. In his opinion palliative care has failed in its mission to care better for dying people because it adopts an institutionalized healthcare approach (it locates care in hospitals and hospices). By doing so it unwittingly devalues the patients and families in its care. Sinclair proposes that home is best and proposes a “Social Role Valorization model” which values the creation of a caring environment within existing communities, rather than separating people from their home and familiar environment to care in an adapted and somewhat sterile clinic environment. He is certain that home care is ideal care, and this study concurs with him in that home care, in some instances, may be ideal care. Yet, in other instances home care may be problematic and challenging. Home care may not be ideal for several reasons including that caregivers may experience emotional stressors when caring, and literature supports this study’s finding that caregivers can experience emotional and other types of distress:

Home care workers experience psychological and communication problems, such as coping with their own sense of loss and dealing with difficult questions. The emotional impact of caring for patients and their families needs to be acknowledged and appropriate support and supervision provided. (Delvin & McIlfatrick, 2010)

African-based studies find that home care may not always be ideal as caregivers express a sense of frustration, exploitation, anger and helplessness (Motswasele & Peu, 2008). African home care may not be ideal as it may entrench gender inequalities in that women are expected to carry out tasks associated with care and are poorly financially compensated for doing so (Akintola, 2006). Kangethe (2009) noted that HBC was gender skewed, and caregivers can take out their frustrations on patients: patients and caregivers can become involved in conflicts and wrangles. Home, as a place for palliative care, may be an uncertain space as care can be both rewarding and challenging.

10.3.2 Hospital care

The espoused curriculum noted that offering palliative care within a hospital context will be of benefit to the patient. Caregivers in some respects concurred with curriculum because they noted that a hospital context would benefit their patients:

It seems to me that the patient is very happy to see a hospital and when there is a nurse there the patient is going to get help. (J 250-251)

A hospital context would provide caregivers with equipment required for their practice. One caregiver eloquently uses the term “chopping wood without an axe” to describe a need for medical or hospital care; she required analgesia for her patient and none was available.

A hospital context for care was not always beneficial and doctors sometimes displayed authoritarian care and the nurse felt relegated to being solely a messenger between the doctor and patient. Literature notes that palliative care is influenced by the dominance of a medical perspective (Dahlborg-Lyckhage & Liden, 2010).

Such a medical context may not always be appropriate; for example, in a South African context an assumption that hospitals will act as an appropriate back-up for care may be unfounded. In hospitals, patients to all intents can become invisible (Gibson, 2004). Gibson draws on the work of Foucault when discussing invisibility in hospitals, and an important aspect of hospital and medical care is what Foucault (2005) labelled 'the medical gaze'. Foucault (2005, p. 109) describes the medical gaze as follows:

First it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention. Moreover, it was a gaze that was not bound by the narrow grid of structure, but that could and should grasp colours, variations, tiny anomalies, always receptive to the deviant. Finally, it was a gaze that was not content to observe what was self-evident; it must make it possible to outline chances and risks; it was calculating.

The gaze has become a metaphor for the processes whereby technologies discipline both the mind and body of the individual. Gibson (2004, p. 2013) notes that transformation from an oppressive State system to a democratic South Africa has impacted in particular ways on the hospital setting, and hospitals cannot be guaranteed to care for a patient as the gaze which is assumed in the North is absent from the South. Patients can be watched excessively in the North and can be ignored in the South. In South African hospitals patients may be subject to physical abuse (Kruger & Schoombee, 2010) and thus hospitals cannot always be relied on to back-up home care.

Liaschenko (1994) asserts that there is a risk with the gaze of medicine when caring at home and is concerned that the norms, values and routines that characterize much of medical care can be transmitted to HBC. Home care may change the "landscape of the home" and may not support patients' abilities for agency and choice of care.

A home care arena may simply offer an opportunity for a gaze or a lack of gaze in medicine to be deployed to the home. Providing home and medical care are challenging, and this study exposes that there are no certainties, due to material circumstances and not due to ideological or theoretical considerations, for the positioning of palliative care in rural homes or in hospitals.

10.4 Roles of caregivers

In this section I look at the roles of caregivers and in particular roles in cancer care, physical care, poverty care, spiritual care, cultural care and communication work. I also look at ambiguous roles.

10.4.1 Cancer care, not HIV care

The curriculum placed great emphasis on cancer care and caregivers reported that the nurses' palliative care curriculum focused on the role of a caregiver in cancer, rather than HIV care. This emphasis may reflect the development of palliative care in a Northern context; cancer is a common life-threatening illness in the North, as illustrated in Table 8.

Females	Males
Ischaemic heart disease Cerebrovascular disease Influenza and pneumonia Dementia and Alzheimer's disease Chronic lower respiratory diseases Cancer of trachea, bronchus and lung Cancer of breast	Ischaemic heart disease Cerebrovascular disease Chronic lower respiratory diseases Cancer of prostate Cancer of colon, sigmoid, rectum and anus Cancer of lymphoid, haematopoietic and related tissue Accidents

Table 8: Causes of death in the UK, 2008

Causes of death, UK, 2008)

HIV is not a common life-limiting illness in the North. I am not suggesting that palliative care curriculum designers in the South should not neglect cancer, as it is becoming increasingly prevalent; cancer rates in Africa are expected to grow by 400% over the next 50 years (Morris, 2003). Studies indicate that in South Africa a third of patients with cancer had severe pain and were in need of palliative care (Beck & Falkson, 2001).

In the context of this study, HIV is a more prevalent cause of illness than cancer, as I illustrate in the following few paragraphs. In providing the reader with an awareness of the enormity of the HIV epidemic I quote statistics from an annual study carried out on behalf of the National Department of Health in South Africa (Avert, 2010).

Every year researchers take blood samples from pregnant women who are attending antenatal clinics and test these anonymously for HIV infection. In 2009 blood was taken from 32 861 women and it was estimated that 29.4% of pregnant woman were HIV-infected: almost one in every three women of child-bearing age is HIV-infected (Statistics South Africa, 2010).

In some areas of KwaZulu-Natal (where this study is set) half of pregnant women had HIV in 2009. In the context of this study, people may not be able to access medication known as antiretroviral therapy (ART) which is required for survival, and statistics indicate that many people are dying as a result of HIV. A report in October 2008 reveals that the annual number of registered deaths rose by a massive 91% between 1997 and 2006 (Statistics South Africa, 2006).

In a critical stance, a curriculum which places ‘undue’ emphasis on cancer and not on HIV could be viewed in terms of a hidden curriculum. A hidden curriculum explores a dissonance between what the curriculum espouses to do and what it does, and the unmediated effects and spin-offs of curriculum. In a South African context, Buckland (1982) notes that a curriculum apparently designed to achieve equality may actually be intended to achieve the opposite. For example, a medical curriculum may discuss pain control for HIV and may discuss that analgesia needs to be taken with a high-protein diet and vitamins. A curriculum can provide a long list of high-protein food and yet many families may not be able to afford any of the food on the list. The curriculum may “spoon-feed” caregivers information around some aspects of palliative care and yet act to keep caregivers ignorant of the degree of social deprivation and need. The hidden curriculum would act to ensure that those who are marginalized remain marginalized. A hidden curriculum describes a notion that structures of education teach much that is not included in the official curriculum. Olthuis and Dekkers (2003, p. 930) discuss the hidden curriculum in medical education as follows:

Medical training is a process of moral enculturation into the medical community. This process of enculturation is usually not explicitly expressed in the formal curricula of medical schools. It is referred to what is called the “hidden curriculum.” During medical education students become socialized. They adopt and internalize new values, attitudes and rationales about what is important in practicing medicine and how to be good doctor ... The emphasis on theoretical knowledge and practical skills distracts attention from the doctors’ moral attitude.

As I alluded to in earlier discussion, this may imply that doctors are empty vessels who simply and uncritically absorb information.

By emphasizing issues such as cancer and not HIV, the curriculum could also be regarded as a null curriculum: a null curriculum implies that topics not included in the curriculum are not important (Eisner, 1985). The emphasis on cancer care and not HIV care may be regarded as rendering the curriculum unsuitable for care in an African context.

10.4.2 Pain care, not poverty care

The curriculum placed emphasis on pain care, and caregivers reported that the curriculum emphasized pain and symptom management:

Palliative care is about pain and symptom management. (L 310)

This caregiver (a nurse) may not understand or value all that palliative care advocates and for some reason she focuses on pain and symptom management. With regard to HIV, in the North patients report symptoms such as pain, often with a high level of associated distress (Krause, 2005). The nurse’s palliative care curriculum may reflect that pain is commonly reported by patients in the North. In this study caregivers implied that they faced greater challenges around social issues than around pain.

Their roles included trying to source food and shelter, supporting patients to take medication and providing respite care for their relatives, and the value of these services may need to be considered by palliative care curriculum designers. When a patient did report pain, the caregivers felt powerless to assist. A study among HIV patients in Rwanda revealed that the greatest needs of patients were not pain but were rather related to psychosocial needs and financial support, with three-quarters of the sample requiring social support (Uwimana & Struthers, 2007). Having said that, it is worth noting that half of the sample did require pain control. There is no uncertainty in practice around a need for both pain care and social care.

This study indicates to palliative care curriculum designers the importance of balancing other issues with pain care, as neither curriculum designers nor a caregiver can predict what type of care a patient will need.

10.4.3 Pain care, not spiritual or cultural care

The curriculum placed a high emphasis on pain and symptom management. A lack of pain alleviation may increase a need for spiritual care in order to try and make some meaning from suffering. Separating pain care from spiritual care, especially when analgesia is not available, may not be possible as the two are deeply intertwined as part of suffering. In this study caregivers discussed the importance of spiritual aspects of caring:

They wanted to call the ancestors and the hospice-staff said that they were not allowed to do this.... It is a difficult situation. (J 331-339)

In the UK nurses criticized their palliative care teaching as inadequate as they perceived that it focused unduly on providing knowledge and skills around physical care of the dying (including pain and symptom control). Nurses felt that curriculum relatively neglected other important aspects of caring, such as spiritual care of the dying (Deeny, Johnston, Boore, Leyden & McCoughan, 2001, p. 100). This suggests that a curriculum for palliative care in the North can also become uncertain around aspects of care.

The nurses' palliative care curriculum emphasized a role of caregivers in managing pain and other symptoms, and caregivers illustrated that cultural care was vital. Culture is of course a complex, multi-faceted notion and cannot be thought of one-dimensionally. The post-structuralist theorist would deconstruct "culture" in an attempt to show the multiple possible meanings of the word. Caregivers implied that a decision whether to include issues around culture and traditional medicines appeared to be at the discretion of the lecturer:

We used to share more than anything about the culture. I think Sister Francis has an open mind. She said that African people have their own rituals and they should be allowed to practice those rituals because those are the rituals. (J 332-334)

It is interesting how this white trainer acts to "other" African people, and this speaks of differences between the trainer and the African nurses she trains.

10.4.3.1 *The importance of culture and indigenous knowledge*

Knowledge around culture has been referred to as indigenous knowledge (IK). I acknowledge that any IK may not be pristine and uncontaminated as it may be historically influenced by Christianity and colonization in Africa. In South Africa IK was found to be valued, especially in rural areas (Moos, Struwig & Roberts, 2010). More than half of a sample of 3307 participants felt that modern medicine and science does more harm than good, and two-thirds felt that IK would benefit more people than science. Many felt that IK should be included in the education of children and that children should respect IK. Three-quarters felt that IK should be part of universities and vocational training institutes. Osberg (2009, p. 1) observes:

Different cultures often have different ethical values and beliefs so there are different views about what education should be trying to achieve. Furthermore, there is no way of adjudicating between differing norms - between different understandings of good or right actions - without falling back on a particular moral or ethical tradition, some subset of norms from which we continue to evaluate what is good and what is right. There isn't a value-free position from which we can determine which values or norms are "best".

Cultural issues are complex and although we may not be able to determine a “best” value or norm, the study of ethics and universal human rights may assist us to ensure that cultural practices do not entrench hegemony. A curriculum for palliative care may have to consider values and norms which are not prevalent in a Northern context. Dr Andrew Ross, a doctor who was based at a hospital in rural South Africa, illustrates the importance of knowing about culture:

Almost everyone in Ingawuma in KwaZulu-Natal will visit a traditional healer before they come to visit us at the hospital and probably after seeing us at the hospital. If they have got TB and they are coughing or vomiting up blood, they think that they have been bewitched, then you need to go and see the traditional healer, who needs to unbewitch you. (Oppenheimer & Bayer, 2007, p. 106)

With specific regard to palliative care, literature notes that claims that spells cast by witches to cause death are viewed in the North as evidence that Africans are superstitious and that their ontological commitments are not amenable to the kind of empirical grounding that is required for theory formation and for subsequently explaining natural phenomena (Brown, 2004). Brown (2004) challenges this notion and suggests that African thought is not grounded in superstition and that its metaphysics are empirically grounded. The deceased can assist the living sections of their families and provide and exercise moral leadership (Teffo & Roux, 2000). The ancestors play an active and vital role in group solidarity and in traditions. Ancestors have a “material existence”, and the ancestor is still part of life as long as the ancestor has offspring and is remembered (Teffo & Roux, 2000, p. 141). In some Christian religions the deceased are also considered to be able to influence the lives of the living (e.g. Catholics pray to Saints). What we are capable of seeing depends upon beliefs we bring to our experiences. Seeing life through the conceptual lens of others may increase the depth and enrich the breadth of our conceptual scheme, and such growth may foster the development of wisdom. This discussion is a cry for palliative care curriculum designers in Africa to acquire an informed perspective on traditional African thought and culture.

Palliative care curriculum designers could potentially learn from traditional Zulu culture and its associated IK as this culture fosters a concept of “self” which is holistic, with little differentiation between mind, body, soul and spirit (Boon, 2007). A concept of holistic care is integral to palliative care.

10.4.3.2 *The importance of traditional medicines*

The curriculum relatively neglected traditional medicine and caregivers alluded to the importance of traditional medicines when caring at home:

For example, we traditional Zulus have had our own traditional herbs that could help the patient. You know like if the patient had a sore they were able to put some herbs to heal it, if the patient had diarrhoea they had medicinal substances that they could prepare and give to the patients. (L 320-323)

A palliative care curriculum may need to discuss traditional medicines as Zulu people may be very aware of these. In South Africa the former Minister of Health promoted traditional medicines and advocated “natural remedies” such as beetroot and garlic as a treatment for HIV disease, and this was discussed at length in all media. Traditional Zulu medicine is associated with homeopathy, and homeopathy is practiced in many areas of the world and some forms (such as Chinese homeopathy and Hindu ayurvedic therapy) appear to be more “scientifically” acceptable than African homeopathy. There may be several reasons for this.

Lessons learnt from integrating cultural issues into a palliative care curriculum could be used to guide palliative care curriculum in the North: in the North healthcare professionals are increasingly caring for patients who hail from a culture differing from their own (Tulman & Watts, 2008). Research has identified that people from cultures other than Anglo-Northern cultures experience poorer health outcomes than their Anglo-Northern counterparts, due to differences in their ability to access health services, including language challenges, and due to institutional racism where organizations fail to provide culturally and linguistically appropriate services to people of different cultural backgrounds (Naravanasamy & White, 2005).

In a post-structuralist stance, an awareness and acceptance of differences are considered to be vital to produce and maintain socially just healthcare systems, and palliative care curriculum designers could use an opportunity to look at cultures as one way of promoting ethical and effective palliative care systems.

10.4.3.3 *Challenges of IK*

It would seem certain that curriculum should highlight IK and culture; however, caregivers discussed that in some instances IK associated with traditional healers could be challenging. Traditional healers could be unscrupulous: “Sometimes people want everyone to come to them and they share over the radios that there are people that can cure AIDS” (L 340-350). Marcus (2007, p. 27) describes other potential challenges around traditional healers:

I just went to the *umthandazi*⁶² and he went to the doctor and several other Inyanga that used to treat him. They said he was bewitched. There were several Inyanga that he went to. All our money was spent on them including the goats we kept.

Marcus implies that traditional healers tried to treat a patient with AIDS using a traditional epistemology and IK (by curing bewitchment). They did not consider alternative epistemologies and as such IK may prove disadvantageous to patients. Women and children may be marginalized by cultural attitudes. For example, in Nigeria ill children are treated badly, as children are considered to be a means of continuing traditional lineage. If lineage cannot be assured than the ill child is considered to be of little worth and so may be neglected (Adejuyigbe & Odebiyi, 2006). In Ghana early death can be viewed as the result of evil action (Harding *et al.*, 2010b, p. 30). While acknowledging the centrality of IK, its application as part of palliative care training and practice is contingent upon many factors, that may not apply to all contexts.

⁶² *Umthandazi*: A traditional healer.

10.4.4 Communication work: Troubled by speech, disturbing the silence⁶³

The curriculum espoused that a healthcare professional should determine whether a patient wants to know their prognosis, and if so the patient should be told the “bad news”. Caregivers described that they sometimes did not want to tell patients about impending death, and this alludes to “killing the messenger”:⁶⁴

I try to be positive because I can't tell straight. If I see this thing is wrong I can't tell the patient that you will die. I can't tell the patient I can't help you. I can always help. (Z 326-327)

The caregiver is perhaps relaying news from another source (e.g. a doctor) or is perhaps reiterating information that another person has given the patient (earlier the doctor may have told the patient that they face death). Telling a person about their imminent death becomes a troubled speech as the caregiver must be certain that the patient faces death and must be certain that the patient wants to be told that they face death. Caregivers describe instances when families were troubled by speech:

I was chased away as one family member said to me, “You have come to predict that someone in this family is going to die”. (P100-109)

Caregivers may have unwittingly disturbed the family's silences. Marcus (2002 , pp. 32-34) describes how some people talk about impending death and some do not:

The child would be disturbed at school thinking that I would die at any time.
It is better the child finds out when I am dead.

⁶³ I take the title of this section from *Democratic Dialogue in Education. Troubling Speech. Disturbing Silence* (Bloer, 2004).

⁶⁴ By “killing the messenger” I use a metaphoric phrase used to describe the act of lashing out at the (blameless) bearer of bad news.

My child is eight years old and I will talk to him when I am in pain.
I will tell him. I would say now I am dying. I will leave you with your
granny, my mother.

In Zulu society some people would want a caregiver to talk about dying and other people would not, and this is not unique to this culture. Telling of death must be based on a certainty of death. Literature reveals that some patients in the context of rural KwaZulu-Natal prefer not to discuss issues relating to their illness and use avoidance of awareness or denial as a coping mechanism (Rabbets & Edwards, 2001).

Superficially it would appear that telling the patient about bad news would enhance autonomy and beneficence as the patient and doctor could make a joint decision around ongoing care. A study on a practice of truth-telling in the care of dying patients revealed that doctors informed patients of their approaching death using three basic styles: 'telling what patients want to know', 'telling what patients need to know' and 'translating information into terms that patients can take' (Miyaji, 1993). These styles are supported by five basic normative principles: 'respect the truth', 'patients' rights', 'doctors' duty to inform', 'preserve hope' and 'individual contract between patients and doctors'. The study found that dialogue between a doctor and patient gave an impression that patients have control over obtaining information, but close analysis of their accounts showed that doctors held power to control information through their management of the information-giving process. Sharing power by truth-telling is not all that it appears to be.

Findings from this study reveal that both caregivers and their patients were troubled by speech, and developing a curriculum around whether or not to disclose a prognosis of death is challenging. Silence is complex, and while it is common to view silence as the opposite of speech, silence also complements speech. Intentional silence may be a deliberate cultural practice that aims at facilitating introspection and self-discipline (Dauenhauer, 1980). Speech and silence are essential parts of human communication, and a patient may accept their approaching death quietly without having to verbalize an awareness of it. Dichotomization of speech and silence may mislead us to devalue silence and privilege speech. Palliative care curriculum designers may need to acknowledge that speech and silence may represent false dichotomy, and may need to develop a new understanding of

communication between caregivers and their patients and an importance of maintaining hope when delivering any bad news may need to be stressed.

10.4.5 Ambiguous roles in practice, definite roles in theory

Caregivers described that they washed patients and spent time with them while their relatives took a break. They sourced food and money and encouraged patients to continue taking medication. They referred patients to a clinic or hospital and spent time listening to the concerns of their patients. Caring at home presented them with having to carry out many roles, and they acted as nurses, spiritual counsellors, social workers, bereavement counsellors and adherence counsellors. They provided food and other resources and were viewed as a friend or a neighbour in their community. Caregivers portrayed ambiguity around what should be a caregiver's role; for example, caregivers were unsure of what their role should be and what community and family roles should be:

There are those who expect you to do the whole thing now. They expect you as a nurse to bath that patient; to come and feed that patient and to come and change the dressing ... They just don't want to do anything for that patient. (T687- 691)

In the UK a study reviewed the roles of a home care (district) nurse, and nurses highlighted that caregivers were somewhat ambiguous about their roles (Walshe & Luker, 2010). They were not always sure of what was expected from them or from other caregivers. Studies indicate that an ambiguity of roles can be associated with an ambiguity around a concept. For example, in England nurses described that they experienced an ambiguous conceptualization of health promotion, and this may speak of an uncertain curriculum. They became uncertain about what was expected from them and uncertain around how to translate their training into practice, because they did not really know what health promotion was (Holt & Warne, 2007). In health promotion nurses felt they had some role to play and looked towards policy for guidance. Holt and Warne (2007, p. 379) describe a gap between “*policy, rhetoric and a reality of practice*”, and conclude that nurses often lack knowledge and confidence and do not know how to develop health promotion among their patients.

In a Northern arena literature notes that the roles of palliative caregivers at home need to be unambiguous, suggesting that practice needs to become certain:

The role of the home-care worker needs more clarity to avoid inconsistencies in practice, unrealistic expectations and ultimately help to reduce the stress experienced by home-care workers. It is therefore important to have clarity, not only on the role, but also the educational and training needs of home care workers. (Delvin & McIlfatrick, 2010, p. 200)

In this study caregivers were unsure of their roles, and literature proposes that a role should be clear and well-delineated (Delvin & McIlfatrick, 2010, p. 200); this is required since caregivers, for example, need to know when to refer for advice. In a rural area of Africa where caregivers work in a relatively unsupported environment, a curriculum cannot foresee all the potential roles a caregiver may be faced with. The official and well-delineated role, as espoused in theory, may be untenable in context.

10.5 Palliative care as expertize and requiring an evidence-base

The nurses' palliative care curriculum was certain that palliative care should be 'specialized care', and as such people offering such care could be regarded as professionals or experts. Caregivers referred to themselves as "experts" in palliative care (L310-313). In a critical stance, professionalism is regarded as being used to convince, cajole and persuade employees, practitioners and other workers to perform and behave in ways which the organization or the institution deem to be appropriate, effective and efficient (Evetts, 2003). The meaning of professionalism and expertise is not fixed. In this section I discuss the following: experts in theory and not in practice, expertise as power and evidence-based practice.

10.5.1 Experts in theory, not in practice

Caregivers implied that they were expected to be experts in aspects of palliative care, such as pain control. However, such expertise was not a significant role in home care.

The expertise identified by curriculum designers was not the expertise required in practice, and caregivers were unable to translate a theory of expertise to a practice of expertise, for example due to lack of equipment.

10.5.2 Expertise as power

The espoused curriculum implies expertise to be advantageous when offering palliative care, and this study revealed that being an expert was sometimes disadvantageous in practice; for example, caregivers described that doctors, nurses and pharmacists (who have expert knowledge) can exert a form of hierarchical power, and in protecting their expert knowledge they do not appear to care for patients:

They don't believe you sometimes. They think you are exaggerating. Yet the nurses are human beings. They treat the patient as a specimen, which is not right. (J 624-625)

Cohen (1998) discusses a concept of “shared power” between healthcare professional and patients, and questions whether an ideal of shared power can be realized in a hierarchical health care system. By interviewing staff and patients, she found that nursing practice was not client-driven and most patients had experienced authoritarian health care relationships with unequal control of resources. Henderson (2003) interviewed nurses and patients within four Australian hospitals and found that nurses saw the giving of power as sharing information and decision making with patients. However, most of these nurses were unwilling to share decision making, believing that they were the ones with health care expertise. These studies provide a bleak outlook as to the exercise of power by health care providers, but is this the same in palliative care?

Power expressed through control is particularly important for patients in palliative care, as patients who face death are extremely vulnerable, and little is known about the types of control that patients experience or prefer during the end of life (Volker, Kahn & Penticuff, 2004). Studies have been conducted that include an analysis of power in the patient-nurse relationship, but these have been located outside of home-based palliative care and outside palliative care in general (Oudshoorn, Ward-Griffin & McWilliam, 2005). Moving palliative care from a hospital to a home may have potential impact on a power balance between nurses and patients, as shifting caregiving to the home holds the potential to increase client-centred care, client involvement and empowerment (McWilliam *et al.*, 2001).

However, the converse may be true, as Giddens (1981) describes a duality of power in as much as power can be used to both liberate and limit (or dominate).

Extrapolating this duality into nursing practice, nurses may have the ability to facilitate patient empowerment and challenge marginalization; however, nurses themselves may be guilty of perpetuating oppression (Wilkinson & Myers, 1999).

According to Foucault (1980), whenever there is power, there is replication and resistance: the patient will wish to assume power and do so by resisting the nurse. We may have seen potential examples of resistance by patients when, for example in Thandeka's and Lungi's conception's patients' families refused to assist with nursing duties (L 320) (T 687-691). Thandeka notes that she cannot convince a family to change (T 421-424) (T 480-495). Thandeka and Lungi may have been unconsciously wielding power, and the family may have been unconsciously resisting. The nurses may be exerting power over patients because they feel disempowered. Jabu specifically notes that she feels disempowered (J 421-424). The exercise of power by patients and nurses creates experiences of both liberation and oppression. Jabu specifically described a sense of powerlessness when she felt that managers of her organization were not paying attention to her ideas or concerns. Literature notes that managers could foster nurses' power within their workplaces by involving them in decision-making processes (McWilliam *et al.*, 2001, p. 54). Nurses who are willing to reflect on and change disempowering aspects of the patient-nurse relationship and nurse-manager relationship, including a harmful hierarchy, will ultimately be successful in caring for their patient within home based palliative care (McWilliam *et al.*, 2001, p. 58).

10.5.3 Evidence-based practice

Curriculum espouses that an evidence base was necessary for practice of palliative care, and caregivers noted that they did not always require a scientific evidence base for practice in context:

It is not scientifically proven and it is not tested in laboratories but traditional healers do work as most of the time it is about faith. If you believe in something that is going to help you then it does help you even if it wasn't designed to care for the illness that you are having. The mere fact that you believe that it is going to work will help you. (T 92-96)

In some instances caregiving was shaped by issues other than scientific evidence, such as IK. Some regard evidence-based practice as a type of practice modelled on Western-based medical science (Gough, 1999). There has been a drive towards using evidence-based practice for curriculum development and educational inputs (Slavin, 2002). Evidence-based practice seeks causal and quantifiable links between specified educational inputs (such as policy, curriculum, pedagogy) and learning outcomes - what works to achieve a desired outcome.

Advocates of evidence-based curriculum argue that educational inquiry should be modelled on the types of scientific research procedures exemplified by large-scale experimental randomized controlled field trials (Slavin, 2002, p. 16). There are instances in education research when an evidence base is necessary, such as teaching nurses about the dose of a medication. However, there may be other instances in education where seeking evidence of “what works” reduces complexity of the issue under investigation in ways that can produce too simplistic conclusions. For example, Tanner (1998) looks at the significance of early life experiences on adults who have an awareness of environmental awareness. He writes:

The rationale for such research is simple: if we find that certain kinds of experiences were important in shaping such adults, perhaps environmental educators can, to the degree feasible, replicate those experiences in the education of the young.
(Tanner 1998, p. 366)

The naivety of assuming that what worked for environmentally aware adults can or should be replicated is exposed in a number of subsequent critiques on life experiences research (Gough, 1999). Thomas (2010) points out that the mere use of the word “evidence” is often taken to be enough to clinch an argument. He asserts that we must be cautious in claiming that we have better evidence than anyone else (Thomas, 2010, p. 15). Evidence becomes based on the interpretation of evidence. Evidence-based practice can be viewed as an effort to close a gap between theory and practice; a “gap-closer” (Gardner, 2006, p. 7). By gap-closer I mean that an evidence base aims to standardize and generalize so what applies to practice in one situation can apply to practice in another. It assumes that there are no gaps between theory, evidence and practice.

An evidence base may rely on laboratory research, testable and controllable entities and hypotheses which can be evaluated by clinical trials. Requiring an evidence base raises questions of where do palliative care practices come from? Practices in palliative care may not come from efficacy studies in response to direct questions; they may have arisen in response to different imperatives or triggers, such as patients' experiences of illness and care. These are deep issues in palliative care which require sustained inquiry and often are not immediately amenable to quantification, causation or comparison. Critical researchers could argue strongly against evidence-based practice as a sole way forward for palliative care. After all, the evidence is based only on our current value systems, which can dramatically alter with new advances in our understanding of nature (Gardner, 2006, p. 7). Rather than accepting the proposition that palliative care should follow an example of evidence-based (or Northern-based) practice and research, we should perhaps also consider the implications of adopting other understandings of evidence. I share with Kappeler (1986, p. 212) antipathy to the conventional ways of concluding a text:

I do not really want to conclude and sum up, rounding off the argument so as to dump it in a nutshell on the reader. A lot more could be said about any of the topics I have touched upon ... I have meant to ask questions, to break the frame ... The point is not to set answers, but to make possible a different practice.

10.6 Conclusion

This chapter juxtaposed data with published literature to deepen and broaden the reader's understanding of the data. It was noteworthy that caregivers had been exposed to a practice of caring for the dying and bereaved prior to their palliative care training, and they referred little to their curriculum experiences. It may be that their prior experiences of caring, rather than curriculum, form a potent driver in their practice of palliative care. Their practice may become certain while the curriculum was uncertain. Literature indicates that the delivery of a curriculum by a person outside the culture of the learners and in a place away from practice may present challenges for learner and teacher. The teacher and learner may have diametric worldviews around issues such as language, place of caring and caring within a team, and literature considers that differing worldviews may introduce complexities and can act to oppress.

Delineating those who are cared for in terms of a life-limiting illness may introduce a false dichotomy in homes in rural areas, as we may not be sure if a person has a life-limiting illness or not. A life-limiting illness has many potential interpretations and may be an empty signifier. Literature reaches no consensus around who should be cared for and when palliative care should be offered. Some authors propose that palliative care should be provided when curative care has failed, some advocate that it should be provided simultaneously with curative treatment, and some purport that it should be provided according to need irrespective of prognosis. Some have moved away from the term "palliative care" and use terms such as "quality of life care".

The curriculum advocated the home as an ideal place where palliative care can be delivered, and caregivers and the literature were less sure of the benefits of home care. Literature supports findings from this study that home care may be appropriate care as the patient can be cared for in familiar surroundings. It also supports the finding that home care may not be appropriate as caregivers feel anxious and unsupported. The espoused curriculum advocated that a hospital would provide back-up for home care, but this view was not supported by caregivers' data. Literature reveals that hospital care presents its own challenges around power issues and neglect and/or patient abuse.

Palliative care largely lies within a healthcare arena, and a significant (48%) role advocated by the espoused curriculum is pain and symptom relief. Caregivers were less certain that their main role should be pain control, and literature points to the importance of other roles including spiritual, cultural and social care. Literature was sure that the role of a caregiver should be well defined, but in practice caregivers were involved with ambiguous social, cultural and spiritual and communication issues. For example, they were unsure of how to address starvation and poor housing conditions. They were unsure around how to protect themselves from personal danger, and could not always be sure that a patient wanted to discuss problems with them.

The espoused curriculum advocated that palliative care should be a form of specialized/expert care, and views of caregivers supported curriculum in that caregivers should be experts in pain control. Literature around expertise and specialization leave us unsure about whether it is a good thing to be an expert and whether palliative care should be regarded as specialized care. The espoused curriculum placed great emphasis on a need for evidence-based practice, and literature supports that an evidence base is required for certain aspects of curriculum and education. However, producing an evidence base may lead to simplification of complex issues, and conclusions thus drawn may not be particularly useful in practice.

I hope that I have conveyed the complexities between curriculum and practice. In the last part of this study I draw on these complexities to reach a thesis around curriculum.

PART FIVE

THE THESIS

Part Five forms the last part in this study that focused on what happens when a curriculum developed for one context is transposed to another context. This part presents the thesis for the study and focuses on study question number four: What is the nature of the palliative care curriculum in context? In this final part I answer this question theoretically by engaging with the data that were generated and analyzed. In answering this question no new data are produced, and I use insights gained from data analysis to formulate a thesis for the study.

In this study the context for palliative care practice was rural homes, and Part Two provided deep foundational knowledge through published literature on palliative care, curriculum and rural home care. In Part Three the reader was introduced to critical and post-structural worldviews and a rationale for using a visual and interview methodology was explained.

Part Four presented data on a preactive curriculum and from caregivers as a form of interactive curriculum. Convergences and divergences between the two were exposed. In deepening an understanding of the data a dialogue was opened between data and published literature. Part Five draws all parts together to produce a thesis. The previous four parts were presented largely from a critical perspective; this part moves more towards a post-structural perspective for “meanings-making”⁶⁵ of the study findings.

⁶⁵ I use the term “meanings-making” to remind the reader that the findings are not one-dimensional and there are many meanings which could be allocated.

CHAPTER ELEVEN

Curriculum certain; practice uncertain:

Palliative care in context

11.1 Introduction

This study focused on context, curriculum and practice and as such may be different to other studies which a doctor, nurse, curriculum designer or HBC worker would read. Aspects of it may be unsettling. Usually the word ‘unsettling’ has negative connotations as it speaks of uncertainties and discomfort. I use the word in a positive sense, as I hope to open windows of opportunities for the reader to view palliative care curriculum in a new way. I wish to alert the reader to a possibility that curriculum may not be readily transposed and translated and achieved to the benefit of everyone. A curriculum designer may need to be surprised and open to skepticism, surprises and uncertainty in context.

This chapter serves several functions. It provides a brief synopsis and review of salient aspects of the study and decisions to work in a qualitative way, and the interdisciplinary link between curriculum and palliative care. I reiterate important issues regarding curriculum, palliative care and rural homes.

Placing the study in a critical stance with the use of a visual research method allowed me to gather valuable insights into the curriculum and into the experiences of caregivers. I summarize the main findings of the study and find that I must take the reader on a slight detour before I finally present a thesis based on the findings of the study. This detour is necessary to deepen awareness of issues of certainty and uncertainty in philosophy, science and medicine. When I provide the thesis it will become apparent why it is prudent not to provide recommendations based on the findings from this study.

11.2 A review of salient aspects of the study

In the field of palliative care this study is unusual, and at the start of the study I requested suspension of judgement until a reading of the thesis was completed. I hope I have convinced you that the study has made visible that which would not be visible through studies using methods of surveys or laboratory observations, and that this is a legitimate and credible way to add to the understanding of a curriculum in practice.

Placing the study in an interdisciplinary space between education and health science was useful as insights from the study can be used to guide curriculum designers in health sciences and, in particular, in palliative care. Throughout the study the usefulness of considering curriculum theory is apparent, and when health science curriculum designers become aware that there is a problem they may consider looking at the curriculum in an attempt to rectify that problem.

Qualitative researchers place an emphasis on the worldview of the researcher, and I opened the study with a critical view of the world. This paradigm was of importance as I am a white medical doctor who trained in a Northern context, and wished to explore the lives of African caregivers who are different from my social and racial group. In this study I did not focus on objective issues such as medical treatments, scans and tests, I focused on people and in particular on nurses and HBC workers. A literature review revealed that the experiences of caregivers who practice palliative care in African rural homes are absent from the literature. This identified gap in literature and my personal experiences of palliative care provided a rationale for the study and highlighted the need to use a qualitative approach to focus on the stories and narratives of home-based palliative caregivers.

A literature review revealed that there was ambiguity about what the term “palliative care” means, and some ambiguity was presented in data. Curriculum designers may need to take heed of this and be aware that in other areas of the world other terms such as “quality of life care” may seem preferable as this is not explicitly linked to life-limiting or life-shortening. Literature also indicated that palliative care was required as caregivers become distressed, and data from this study supported that caregivers can become distressed. Palliative care curriculum designers may need to prioritize coping skills and support mechanisms for caregivers.

The literature review unearthed some contestations around whether palliative care is required as a response to death-denying in society. I could not draw any generalizations from data around whether society in the context of the study is death-denying, although many other reasons were presented in the data as to why palliative care is required. Some critique palliative care as lying predominately within a health science domain, and this concern is supported by data which indicate that patients' and caregivers' challenges lie well beyond solely healthcare issues. Literature also raised concerns about specialization within healthcare and within palliative care, these supported by data in that expertise could be associated with difficulties in assessing care for patients. Literature also raised issues around palliative care as perpetuating social injustice. Findings from this study indicate that a palliative care curriculum did not consider that analgesia was not available and unavailability of analgesia is unjust. A palliative care curriculum could thus be thought of as perpetuating social injustice if it does not even acknowledge that basic equipment, medication, food, shelter and finances are not available in context.

Nurses and HBC workers proved to be an important source of data. In keeping with democratic participatory validity, I stayed in the background during data generation when caregivers were given freedom to take photographs of issues which they felt to be of importance to them in their practice of palliative care.

Qualitative methods require different approaches to quantitative ones, and I relied on authenticity, trustworthiness and generativity. Triangulation considers whether claims by the researcher are supported by data, and I hope that the reader shares my view that my findings and claims are embedded within the data. The use of a critical stance was useful as it enabled the voices of caregivers to emerge and their voices provided rich data and valuable insights into a curriculum and into a practice of palliative care. Although the voices of patients were not directly foregrounded, their presence was infused within the experiences of the caregivers. The experiences of the caregivers strongly hint at deep sociocultural issues of patients which require further study, and patients may be an important source of information.

Throughout this study I employed Vital's (2003) ideas of exemplarity, transparency and generativity. I used a palliative care curriculum as an exemplar of a situation in which a curriculum is introduced into a context other than that of its origin. I made my research position transparent, and I invited the reader to apply findings to their own context. I sought no universal truth for palliative care.

Vithal (2003) also considers an agenda of tranformativity in critical research, where an explicit aim is to bring about change. I previously discussed that this study does not aim to bring about change, although change may be enacted after the study.

Engaging with curriculum literature illustrated that a curriculum could be regarded as narrow, such as a written syllabus which simply provides a list of topics, or alternatively a curriculum could be regarded as broad when the written, espoused (or preactive) component is considered along with enactment/practice (interactive) (Jackson, 1968). This study considered a text of a palliative care curriculum as a form of preactive curriculum representing a palliative care discourse and experiences (or 'personal discourse') of caregivers as a form of an interactive curriculum. Any curriculum could provide a means of continuing oppression or transformation of marginalized, oppressed people. Literature indicates that palliative care curriculum may reflect positivist ontologies and epistemologies in that curriculum lies largely within a technical type with emphasis on attainment of pre-determined aims and objectives. Literature (Eisner, 1985) called for a practical curriculum which considers that curriculum should be more than leading to the achievement of preordained goals and should consider issues such as the moral and ethical development of the person, interrelated with concerns for the holistic care of patients.

A review of palliative care literature (Connor 1998) exposed reasons why it was developed and these reasons included a view that society was generally death-denying. This death-denying thesis has been questioned and there are tensions and contestations in palliative care literature, although a common theme is relief of suffering. Caregivers' data did not directly reveal information on whether their society is death-denying, and they provided many examples of when palliative care acts or can act to relieve suffering.

Home care is very necessary in the study context as in the South as the patient and caregiver may have no choice of place of care other than home care. A literature review indicated that there are gaps in literature around palliative care curriculum in the South and in particular palliative care curriculum for rural home-based palliative care.

The study was important as it foregrounded the voices of caregivers which would be left unheard within a positivist stance, and their voices revealed profound challenges in practising palliative care.

The study illustrated that an intervention such as palliative care could be confounded by context; for example, relief of pain was confounded as there was no analgesia available. The context becomes as important as the intervention. Positioning the study in rural homes was significant as palliative care is usually practised in hospitals or hospices, and this study revealed challenges which may not be faced in other contexts; for example, accessing support and information may not be challenging in a hospital context.

11.3 Certain the curriculum; uncertain the practice

In this section I review findings that certainties in a curriculum become uncertain in practice. In a critical stance, the palliative care curriculum was found to be strongly influenced by ideas of palliative care emanating from the North, and presented issues which are of importance in the North such as physical care and care of patients who have cancer. Juxtaposing curriculum data with caregivers' data revealed that aspects of the preactive curriculum did not really take into account the context in which the curriculum would become interactive or enacted. In several instances the curriculum relatively or totally neglected issues which were important to the South, including cultural care, spiritual psychosocial care and HIV and AIDS care. In homes palliative care could be offered as a first point of care, which contrasts with timing of palliative care delivery in the North as it is offered at the end of a process when doctors are sure that potential curative treatment has failed. In homes curative treatment may not be available in the first place, as patient may not be able to reach a clinic or hospital.

Aspects of care which are important in the South could affect fundamental ways in which we conceptualize a curriculum for palliative care in this context. For example, in Northern philosophy associated with science is a teleological assumption that reaching the end of a process is important: teleology provides a moral basis for the professional ethics of medicine, as doctors are generally concerned with outcomes and must therefore know the *telos* or outcome of a given treatment (Sugarman & Sulmasy, 2001).

In African cosmology⁶⁶ death is not seen as an end as there is no real distinction between the living and the dead, and caregivers' data indicate the continuing importance of the deceased and ancestors in everyday life.

An idea of "continuing to live after death" would have a profound effect on current certainties in palliative care curriculum, when it is advocated that a person be prepared for "an end to their life" and not for "a continuing existence after death." The use of the term "palliative" may become questionable as it is coined in a Northern context which suggests amelioration before the patient faces a "final event" (death). Mother Theresa understood the need for palliative care in a culture defined by a belief in fatalism and karma, and palliative care curriculum designers may learn from her work.

The curriculum did not consider other important issues which were raised by caregivers, including the dangers they faced. Such dangers included physical dangers in that caregivers could be hijacked or become infected with serious, life-threatening diseases such as MDR-TB, as revealed by the accounts of caregivers in this study. Emotional challenges were presented when patients chased caregivers from their homes or accused them of killing their relatives or being harbingers of death. The curriculum did not consider that caregivers would not be able to access tools and equipment required for practice and that they may experience low levels of support from other healthcare professionals. The curriculum did not prepare caregivers for starving patients who live in shacks and suffer with their entire family. In particular, the curriculum did not prepare caregivers for the powerlessness they experienced, which was entrenched, for example, when curriculum emphasized pain relief in the absence of analgesia in context. A fundamental assumption regarding the cared for, previously unexplored in palliative care literature, was destabilized by findings from this study: can we provide palliative care if we cannot be sure whether the illness is life-limiting or if we cannot have an idea of how long we expect the patient to live? This falls back upon a persistent need for certainty. An inability to access diagnostic or prognostic tools may present profound philosophical and ethical challenges if we try to delineate who we care for. In the North a doctor or nurse is an arbitrator of when to provide palliative care, as they can be fairly certain of when a patient will die from their disease. A decision to offer palliative care may require the presence of a doctor or nurse, and the absence of such personnel can lead to challenges if palliative care is practiced.

⁶⁶ I realize that I am generalizing by using the term "African cosmology".

For example, a patient may be denied access to potentially curative care if an inexperienced, unsupervised caregiver informs them that their disease is incurable.

A palliative care curriculum may assume that a caregiver has support from or access to a doctor or nurse who can provide an informed decision around care, and as such may assume that caregivers form a homogenous group. Nurses and caregivers may be under an impression that they can practice palliative care without input from a doctor or senior nurse and without access to treatment modalities or diagnostic/prognostic tools. A role of a curriculum in this specific context may be to highlight a power differential between HBC workers, nurses and doctors, and it may need to be made explicit that caregivers should not practice aspects of palliative care (such as preparing for death by making a memory box) in the absence of a medically informed care plan. This may sound harsh, particularly in a critical worldview where an aim is to uplift and neutralize power differentials. It is not an intention to appear harsh, cold or powerful - an intention is protect a patient from inappropriate or incorrect information and to ensure that every opportunity for potential curative care is offered. Developing a power differential by delineating the roles of HBC workers, nurses and doctors in palliative care may act to avoid disappointment of caregivers when they may believe that after training in palliative care they may have appropriate knowledge and skills to act independently of doctors or nurses.

In traditional African society it appears that a decision to accept imminent death and not seek further treatment was made by the traditional healer. This poses problems, as the traditional healer may not actually know whether a disease is life-limiting or not; however, this discussion raises an issue of future collaboration between traditional healers, doctors and nurses.

The curriculum appears to be certain, but actually cannot be certain as it does not consider practising palliative care in context. As such, the preactive nurses' palliative care curriculum could be regarded as a hidden curriculum, a null curriculum or a contextually uninformed curriculum. A hidden curriculum will teach things which were perhaps not intended, for example that cancer care is more important than HIV and AIDS care. A null curriculum considers what should be in a curriculum that is not there. In the palliative care curriculum spiritual, cultural and psychosocial care were relegated to a null curriculum.

I am not suggesting that an aim of curriculum should be to teach about specific cultural, spiritual or psychosocial care. I am suggesting that curriculum can alert caregivers to the great diversity of beliefs, rituals, superstitions and social practices which have to be factored in when practising in context. I acknowledge that such beliefs may not exist in forms which are discernible to “outsiders”. A curriculum can prepare a learner for the fact that some things may be unknown or uncertain in context.

People in the South have differing worldviews to people in the North. A hidden, null or contextually uninformed curriculum could ensconce hegemony of Northern ways of thinking. A curriculum may be certain about aspects of palliative care that apply in areas where the curriculum developed. The nurses’ palliative care curriculum was introduced from the North, and largely did not take context into account and presented certainty around several aspects of care. This reflects that palliative care derives largely from a science view which holds that science can be certain and can predict outcomes of interventions.

The reader will glean that certainty and uncertainty have evolved as overarching themes in this study, and at this stage it is necessary to take a detour, while palliative care is suspended, to delve deeper into certainty. In the next few paragraphs I present a brief overview of theories of certainty in philosophy, science and medicine.

11.4 A detour: Looking at certainty

11.4.1 Certainty and philosophy

In providing a brief philosophical review of certainty I draw on the work of philosophers Wittgenstein, Moore and Foucault. Philosophical debate around a search for certainty in knowledge was highlighted in the book *On Certainty* (1969), which took as its starting point Wittgenstein’s response to a paper given by G. E. Moore called *Proof of an External World* (Moore, 1939). Moore tried to prove that there is a world external to our senses by holding up his hand and saying “here is a hand.” Wittgenstein suggested that Moore failed to prove so, because his claim that he *knows* he has a hand invites the question of how he knows. An idea of doubting the existence of a world external to our senses gains a foothold from the fact that any knowledge claim can be doubted and questioned, and every attempt at justification of a knowledge claim can also be doubted and questioned.

We take some propositions for granted (here is a hand), and these propositions can be regarded as an empirical necessity because we need to speak about the hand or about things in the world - these propositions aren't meant to be subjected to sceptical scrutiny. If two people disagree over whether one of them has a hand, it is unclear whether they can agree on anything that might act as a common ground on which they can debate the matter. Communication and rational thought are only possible between people when there is some sort of common ground, and when one doubts such fundamental propositions as "here is a hand," that common ground shrinks to nothing. Behind Wittgenstein's belief that "here is a hand" is a proposition that rests in his insistence on the importance of context, and according to him a proposition has no meaning unless it is placed within a particular context and people within that context must agree that something becomes certain.

Certainty may be regarded as a reflection of dominant societal norms, values, beliefs and epistemologies, and certainty for Foucault was like a red rag to a bull. He argued that power makes the uncertain certain (Foucault, 1975). Certainty holds power. Let me provide an example. John Rock was a physician who developed the oral contraceptive pill in the early 1960s. He was a staunch member of the Catholic Church and felt that he had to reconcile birth control with the ethos of the church. He tried to make the oral contraceptive pill as "natural" as possible by ensuring that the chemicals used mimicked the chemicals of the menstrual cycle. He did so because the Catholic Church condones natural contraceptive methods, such as the rhythm method. However, the church did not accept that the oral contraceptive pills represented a natural method for birth control, and a certainty regarding the "sinful" use of oral contraceptives was presented by Pope Paul VI: *"In 1968, in the encyclical 'Humane Vitae', Pope Paul VI outlawed oral contraception and all other artificial methods of birth control"* (Gladwell, 2010, p. 95). It could be argued that a certainty about a 'sinfulness' of oral contraception has held power over the reproductive lives of many Catholic women.

11.4.2 Certainty and science

A need for certainty in science can be traced back to the work of Descartes and Newton. Rene Descartes (1596-1650) and, slightly later, Sir Isaac Newton (1642-1727) set the scene. The former advocated rationalism while the latter unearthed a collection of fundamental laws. A flood of other discoveries in diverse fields such as magnetism, electricity, astronomy and chemistry soon followed, injecting a heightened sense of confidence in the power of reason to tackle any situation. The scientific approach created a high degree of confidence in the power of human reason to tackle any physical situation.

By the late 19th and early 20th century many scientists believed that few surprises remained to be discovered. More fundamentally, the assumption and expectation was that over time the orderly nature of all phenomena would eventually be revealed to the human mind. Science became the search for hidden order. This view held until the 20th century when in 1996 John Horgan published a bestselling book entitled *The End of Science*. He argued that since science was linear and all the major discoveries had been made, then real science had come to an end (Horgan, 1996).

Some hold a view that certainty in science may be contestable and the neutrality of science is a myth; for example, a study found that certainty could be influenced by context: researchers presented participants with two differing sets of documents and one set had the “scientific study” and another set had the scientific study plus additional newspaper articles on global warming. There was a significant difference in readers’ assessment of the certainty of global warming depending on which set of documentation they had been presented with. The participants who had the report together with newspaper articles produced the highest level of certainty about global warming and differed significantly from the control treatment (with no newspaper articles) (Corbett & Durfee, 2004).

Science itself hovers between certainty and uncertainty. Not all phenomena are orderly, reducible, certain, predictable and/or determined. For example, no matter how hard classical physicists tried, they could not fit the dualistic nature of light as both a wave and a particle into the orderly, classical system. Heisenberg’s uncertainty principle, which shows that one can either know the momentum or position of a subatomic particle but not both at the same time, presents an obvious problem for the orderly paradigm (Heisenberg, 1927).

What this meant was that even at the most fundamental level some phenomena conform to a classical framework of science, and others do not. With this, the boundaries of the classical paradigm of certainty were cast asunder.

Gravity continued to function and linear mechanics continued to work, but science could no longer claim to be universally applicable to all physical phenomena. It had to live alongside phenomena and theories that were probable or uncertain. Uncertainty has been recognised as an inevitable feature of some situations.

Following on a theme of uncertainty in science, consider the p value which looks at a probability that a null hypothesis is not certain/true. A p value is a measure of how much evidence we have to repute the certainty of our null hypothesis, and thus we have to factor in uncertainty. Another example of uncertainty in science involves ‘chaos theory which disrupted the notion of orderly, scientific, linear frameworks. Kellert (1993) reports a phenomenon where small changes in initial conditions lead to radically divergent outcomes in the same system, which he terms “the butterfly effect”, and argued that given the appropriate circumstances, a butterfly flapping its wings in China could eventually lead to a tornado in the USA. Cause did not lead to effect. Order was not certain.

11.4.3 Certainty and health science

Until recently health sciences required and sought certainty, as manifest by reliance on standardization within replicable and dependable systems. In laboratory work standardization and replicability are laudable, and such laboratory study is preoccupied with minute aspects of humans; does a drug work or does it not work? Will the drug work for everyone? In health science a search for certainty lies in rationalism and objectivity.

Subjectivity is generally shunned. Evidence-based medical research courts objectivity and implies that an emotional basis for decision making is of less value than decision making based on non-emotional objectivity. Antonio Damasio (1994), a professor of neuroscience, disrupted a belief that objectivity was of greater use in decision making than subjectivity. He reported that some brain-damaged patients could no longer feel emotion, although their ability to apply reason and logic were unimpaired. He found that decision making was hampered by a lack of emotion:

Delivered from the maelstrom of emotion, these people should have been able to make lucid, rational decisions based on a logical analysis of choices.

In fact it was just the opposite. They were unable to make any decisions, even the most simple. (Foley, 2010, p. 81)

Patients could analyze the pros and cons of each possibility but were unable to choose one possibility over the other. Damasio concluded that intuition, subjectivity and gut feeling are essential parts of decision making. In a context, we can agree that a hand is a hand. We can agree that an apple will fall downwards due to the effect of gravity. We can agree whether a drug lowers blood pressure or not. What happens when we cannot agree - for example, as to what the term “palliative care” means?

11.5 Moving towards post-structuralism to make a thesis

Before presenting a thesis, I acknowledge that working within a critical paradigm I felt that data did not justify a concrete conclusion that there was hegemonic flow of ideas from the North to the South. Such a conclusion does not reflect the multiple nuances and entangled complexities of data. A post-structuralist approach may offer a more balanced way of looking at findings. A post-structuralist view does not prescribe change but rather offers potential critique of potential “solutions” and “recommendations”.

The idea of social justice arose in this study and even if I am reluctant to prescribe a material interventionist, transformatory agenda, I acknowledge that there are discursive possibilities signalled by the study. For one, it is important to include multiple knowledge (e.g. formal, informal, emotional) and also to interrogate these knowledges. For another, it is important to constantly interrogate knowledge/power nexus. Scrutinizing such issues impacts on social injustice in general, and such scrutiny may be particularly relevant in palliative care in South Africa.

In literature, such as that presented by Chattoo and Atkin (2009), there is ongoing discussion about who should be cared for in palliative care; a post-structuralist theorist would acknowledge and accept that this is elusive and hard to pin down.

A palliative care curriculum advocated home care, and yet home care concepts and experiences are not universal.

A brief post-structural review indicated that palliative care discourse is not a neutral way of looking at the world, and discourse presents a large field of discursivity where many ways of caring can become excluded. A post-structuralist view would also acknowledge that an opposite may also occur, where language can create an infinite number of possibilities and meanings.

I have found it necessary to relook at my research position as a “commonality of purpose”, as this position may have implied to caregivers that the study would result in change⁶⁷. The reason why this study does not aim at transformativity will become clear when the thesis is presented.

Moving into post-structural terrain became useful, as it enabled me to come to the thesis based on the findings. A post-structuralist view illuminated the dichotomy between a preactive and an interactive or espoused and enacted curriculum, and binaries in ways of thinking. Throughout the study there have been slippages between a preactive and interactive curriculum, and a post-structuralist view expects that such slippage will occur.

⁶⁷ Earlier in this study, I described that caregivers and I had a sense of commonality for purpose for the research: we both wanted to improve the lives of caregivers who practice palliative care in rural African homes; Vithal (2003, p. 115) describes this as a transformative potential of critical research. At the end of this study, this transformativity aim has become disrupted. I cannot provide concrete recommendation for HBC managers or curriculum designers. In mid-2011 I returned to managers and caregivers and explained that the results of my study were “inconclusive” around how to change a curriculum for palliative care. I reported that the study did reveal that caregivers experienced stress, a sense of powerlessness and were unsure of what was expected from them. I offered to employ a psychologist as an external resource for caregivers. I have linked with the University of New Mexico and have been involved with a study looking at the role of music in rural, home-based rural palliative care. In this music study caregivers are invited to sing in a group at the start of each day and they are invited to use their song as a means to pray and communicate their challenges to each other and to managers. The music study considers whether music could offer them a culturally sensitive means of articulating their concerns to management and to developing a sense of agency in their palliative care practice. I also will promote development of a curriculum for palliative care at the University of KwaZulu-Natal and present findings of this study to a wide audience, including the Department of Health and the WHO.

A post-structuralist view enabled me to look on ideas on palliative care, which were developed in the North and incorporated into the palliative care curriculum in the South, as in some ways useful; for example, it is necessary to know about issues such as analgesia. The palliative care curriculum provided a basis for some sort of care to be initiated, however problematic. The palliative care curriculum could be regarded as a gift to be accepted, taken further, taken apart, rebuilt and enriched to respond to needs.

A post-structuralist view also enabled me to look at issues such as expertise in palliative care and to ask who are the experts? Novices and experts are not related to qualifications. In context, the caregivers become experts in rural spaces and palliative care curriculum designers could acknowledge and make use of such expertise. A highly qualified nurse who has not practised in rural areas with African peoples' beliefs, customs and ideas becomes a novice in this context. A wise rural expert becomes a novice in a highly technologically advanced hospital context. The experiences of caregivers in a context may not only help with shaping a curriculum, but may help with supporting a new generation of caregivers. Experts and novices are contingent with context.

11.6 The thesis: Certain the curriculum; uncertain the practice: Palliative care in context

I now reach the point in my study when I present a thesis and I look at study question four: What is the nature of palliative care curriculum? As I alluded to earlier, the thesis represents a diversion from a critical paradigm. A critical paradigm requires that I have some degree of certainty around oppression and marginalization, a need for change and how to change. Based on the findings of this study, I find that I am not sure what to change or how to change it. At this point in the study I find that I must turn towards post-structuralism to make meanings of findings.

In a post-structural stance, the thesis arising from findings in this study is that the context destabilizes certainty in curriculum. When we think that a curriculum is complete and when we are certain about objectives and outcomes, we find that certainties are destabilized and this destabilization can be noted through practice which becomes unpredictable. The reason why the curriculum presents certainty is because it is a decontextualized and/or contextually uninformed curriculum.

This destabilization of certainty becomes particularly important when a curriculum is introduced into a context other than its context of origin of geographical or temporal space. Certainty operates as a false notion in curriculum.

As an example to support this thesis, let us return to palliative care curriculum and consider certainty. The curriculum is certain that morphine is required for certain types of pain and should be given in specified doses, at specified times, in a specified manner. When curriculum certainty is juxtaposed with context, we see that morphine is required and yet it is not available. Curriculum designers may have been certain that morphine would be available, as it is generally available to those who need it in a Northern context. Looking at a bigger picture, we ask why is morphine not available in this context? South Africa has given much thought and effort to combating the abuse of illicit and legal substances. The Prevention and Treatment for Substance Abuse Act No. 70, 2008, and the National Drug Master Plan 2006 – 2011 seeks to reduce demand, reduce harm and reduce the supply of illicit substances (van Niekerk, 2011). Morphine is a narcotic analgesic which can be taken orally in tablet form, and can also be injected subcutaneously, intramuscularly or intravenously; the last is the route preferred by those who are dependent on morphine.

Morphine is also highly addictive. Tolerance (the need for higher and higher doses to maintain the same effect) and physical and psychological dependence develop quickly. Withdrawal from morphine causes nausea, chills, and sweating lasting up to three days. Morphine crosses the placental barrier, and babies born to morphine-using mothers go through withdrawal. Addictive drugs activate the brain's reward systems and the promise of reward is very intense, causing the individual to crave the drug and to focus his or her activities around taking the drug. The ability of addictive drugs to strongly activate brain reward mechanisms and their ability to chemically alter the normal functioning of these systems can produce an addiction. Morphine also reduces a person's level of consciousness, harming the ability to think or be fully aware of present surroundings. We need to work with some degree of certainty around morphine (its indication, dose, administration route) and we need to work with uncertainty around morphine (will people abuse it?).

Given complexities in a context, one wonders if a curriculum can ever cater for all unfolding lived realities. At the beginning of this study I stated that through the voices of caregivers important information would become available to curriculum designers, to palliative care providers and for people interested in how health science can be improved, and I believe the thesis has lived up to this expectation. I remind the reader that research on palliative care curriculum is particularly pertinent in Africa at this time, as the Palliative Care Declaration of Cape Town 2004 calls for promotion of education in palliative care throughout Africa. This study, although advocating a need to prioritize curriculum theory, advises the curriculum designer to proceed with some caution as issues in caring are complex and changing. In following on from this thesis I ask whether curriculum designers should court uncertainty, and I present curriculum theories which forefront uncertainty.

11.6.1 Should curriculum designers court uncertainty?

In any context uncertainty may be apparent. This may be distressing and confusing to some teachers, curriculum designers and caregivers. Teachers and students may be cushioned by orthodoxy, and uncertainty as a pervasive mode of operation may be crippling, leading to teachers not being able to teach and caregivers not being able to learn or practice. Awareness of many complexities which arise due to a certainty in curriculum could lead teachers who teach with certainty to become hesitant and doubtful of their knowledge. They may be reluctant to present anything as certain and thus become paralyzed by inaction. In life we must work with some certainty and we must work with some uncertainty. In order to work as caregivers we need some measure of certainty and uncertainties should not penalize our work. We know that palliative care has worked in some contexts, but caregivers in other contexts may need to come up with their own ideas and conceptualization as existing conceptualizations and curriculum may not have taught us to prepare for uncertain spaces and uncertain practices.

We can agree that some things can be regarded as certain; for example, we can agree that “a hand is a hand” or that a certain type of pain requires a certain type and amount of analgesia to relieve that pain. A teacher must operate on an assumption that what she teaches is important and useful and not harmful, and that there is some consistency and degree of certainty in the world.

11.6.2 Curriculum theories: Certainty and uncertainty

Maxine Greene implies that certainty (or order) can be disrupted, disordered and renegotiated:

Disorder, in other words, is continually breaking in; meaninglessness is recurrently overcoming landscapes which once were demarcated. It is at moments like this that the individual reaches out to reconstitute meaning, to close the gaps, to make sense once again. (Greene, 1971, p. 258)

Maxine Greene tends to veer towards certainty. She implies that we must expect disorder in curriculum, and in response we reach out to close gaps and make sense again. She implies a seeking of homeostasis.⁶⁸ Homeostasis privileges constancy over change, predictability over complexity and certainty over uncertainty. Other curriculum theorists imply that we should not aim to close gaps in order to make sense of our world, but should aim to accept and negotiate our way through gaps. Theories around accepting and negotiating uncertain gaps can be found in the work of the post-structuralists that have burst onto the curriculum scene since the 1980s (Pinar *et al.*, 2002, p. 514).

Palliative care curriculum developers may wish to learn from the work of curriculum theorists such as William Doll, Cherryholmes and Dagnault, and I present some of their work below. I acknowledge that these theorists work in the North and do not work in a narrow positivist paradigm.

In education uncertainty has been embraced; as an example, William Doll (1989) suggests that we should not aim to close uncertain gaps but should embrace them as learning opportunities. Doll (1986, 1989) was one of the first education scholars to explore the theoretical and practical implications of looking at a curriculum, teaching and learning in terms of emergence⁶⁹ and disequilibrium and their associated uncertainty.

⁶⁸ Homeostasis implies that a system will adapt to reach a state of equilibrium or stability.

⁶⁹ Emergence focuses not on how systems maintain their organization intact, but rather on how they evolve in unpredictable and often highly complex ways (Hayles, 1994). Gaps are sites of emergence and Goldstein (1999, p. 49) writes that emergence refers to the arising of novel and coherent structures, patterns, and properties during the process of self-regulation in complex systems.

Social development is never linear and predictably progressive and is rather uncertain and erratic, and a curriculum may reflect this. Doll encourages us to value that which is unexpected and/or beyond our control. For Doll, the teaching moment seems to take form in the interplay between order and chaos, disorder and order, meaning and meaningless, closure and openness, certainty and uncertainty. He considers that:

Chaos theory and complexity theory give meaning and substance to the language of disequilibrium, reflective institution, surprise, puzzlement, and confusion, zones of uncertainty, non-rationality and metaphor analysis. (Doll, 1989, p. 245)

It is disequilibrium itself that provides opportunities for creative tension and self-reflection. In this study we saw that caregivers have their own experiences, valuations, reconfigurations and self-reflections. Curriculum may need to become explorative, avoid closure, create disequilibrium in the minds of students and encourage multiple pathways and alternatives: the aim of curriculum should not be to close gaps. For example, with regard to morphine a curriculum could cover ways of recognizing drug addicts and provide information on addiction counselling services. Doll (1989) also suggests that a curriculum should be underpinned by general goals which have been negotiated and agreed on by parties involved, including the learners themselves. He advocates that the abiding concern of any learning should be the interrelationship among persons, so that sharing and caring relationships become central to learning:

Mutual inquiry, rather than the transmission of knowledge or production of specific behaviors, is the general framework in which this relationship would be placed. (Doll, 1989, p. 252)

This may happen intuitively in curriculum practitioners; for example, in this study the curriculum practitioner wished to find out more about rituals and encouraged nurses to accept the views of patients regarding these rituals. In this study a caregiver felt distressed because no analgesia was available for her patients, and taking account of Doll's work a curriculum designer could meet with a caregiver to look at ways in which analgesia could become available. A caregiver may have to travel to a clinic to fetch medication or advocate to local government for provision of medication in her context.

Cherryholmes sees that the norm for a curriculum is conflict and instability:

Curriculum is neither historically situated in the tradition or an academic discipline nor constrained by a concrete situation.

The complexity of demands thrust upon the study and practice of curriculum contribute to its looseness, its thrashing about, its contradictions, and its lack of a centre, grounding foundations. (Cherryholmes, 1988, p. 148)

He forecasts that if the curriculum field moves to a post-structural attitude, practitioners may avoid the false hope and goal of certainty and stability. In looking at post-structuralist curriculum theories I was struck by the work of Jacques Daignault; Pinar *et al.* (2002, p. 480) say of him:

more than any other scholar has worked and played, not only with insights provided by post-structuralism and deconstruction, but also within the languages and currents of these movements. (Pinar *et al.*, 2002, p. 480)

Daignault explored spaces, gaps, “in-betweens”, and the differences within language, thoughts, the subject and our ways of conceiving ourselves and curriculum. He looks at spaces in curriculum and attempts to articulate passages across the spaces and between the “in-betweens”. He often uses two terms: terrorist and nihilist. Daignault argues that to know is to kill (Daignault, 1992). In a post-structural stance, knowledge means a reduction of differences, the many to the one, the uncertain to the certain. For Daignault, to know is to commit murder as knowing alienates or destroys an alternative way of seeing something. To know is to be certain, and to be certain is to terrorize. Nihilism refers to the abandonment of any attempt to know: anything goes. For example, with relation to the terrorist, a caregiver may think that a patient is a drug addict and refuse to increase a dose of morphine even though the patient has severe pain. With regard to nihilism, a caregiver may give a patient morphine even though she suspects that the patient is selling morphine to a drug addict. Daignault calls for us to live in the middle, in spaces that are neither terrorist nor nihilistic. In a dualism of terrorism and nihilism it is the thinking in the passage which constitutes an “excluded third or middle”. Regarding a dualism of knowing and being certain of everything (terrorism) and knowing and being certain of nothing (nihilism), he says:

The only way to avoid this fate is to allow thought to think itself.
To go beyond or to disrupt dualism and to think the difference
between them. It is to introduce a paradox. It is not to stop defining,
but to multiply the definitions. (Daignault, 1992, p. 201)

He recommends that we introduce a paradox to enable us to think and that thinking happens only between terrorism and nihilism.

For example, the curriculum designer could present the two scenarios around morphine that I have described above and ask caregivers how they would react. A way forward may be to ask another caregiver, who is not directly involved in that patient's care, to review the use of morphine. A palliative care curriculum could encourage the caregiver to ask questions of the patient, family and others- what are the main concerns in this patients' care? Can I address those concerns? If not can I organize for someone else to address these concerns? If nothing can be done to relieve suffering, how do I feel? Can I accept this?

11.7 Where to from here?

As I close this study, I find it difficult to provide recommendations for a curriculum, as this study has provided a view that certainty in curriculum provides a false security about outcomes. Providing recommendations is contradictory to this thesis, as recommendations may provide a false sense of certainty and security. What I recommend from this study may not apply to another context, and as such it would not be prudent to provide recommendations. Cultural beliefs, superstitions and social issues which are part of one context may not be part of another, and all of these form an uncertain space in which to design a curriculum. Based on the findings of the study, curriculum designers will need to keep in mind that whatever curriculum they design may become destabilized by context. I can recommend one thing - and this is that we should not delude ourselves that we can design a perfect curriculum. In the following discussion I veer towards a curriculum as practised rather than as designed. I hope that I do not present these ideas as foregone conclusions, and rather as thoughts and ideas for curriculum designers.

In an interdisciplinary arena health scientists could learn from educationalists who have been aware of the importance of context and curriculum, and who have flagged uncertainty of context at the outset of any educational endeavour. For example, Amin and Ramrathan (2009, p. 69) in South Africa foreground the multifaceted nature of context by noting that:

The post-apartheid landscape in South Africa is characterized by multiculturalism and homogeneity, multiracialism and mono-racialism, co-education and gender-specificity, class distinctions and class elitism and a range of disparities, inequalities, similarities, and differences between the polarities presented, and beyond.

The authors suggest that context is multifaceted and extraordinarily complicated. Their work is based on a premise that a curriculum cannot prepare a learner for all contexts and that a curriculum should aim to deliberately encounter, factor in and confront an uncertainty associated with a diversity of contexts. In assuming that some exposure to a diversity of context is important, they provide a “*context-driven learning approach*” (Amin & Ramrathan, 2009, p. 72). This approach considers that memory, experience and learning are interconnected processes of the mind. Although their work applied to training of teachers, it could be rearticulated to apply to training of palliative caregivers, and I present a rearticulation of their four-phase framework to a context-driven learning approach below:

- **Phase one: Reframing memory**

Caregivers who are to learn about palliative care have previously learnt about some aspects of caring in various contexts, including hospitals and clinics. Their training may have been relevant to these contexts and may have led to a “circular closure of memory”.⁷⁰ This view suggests that as a result of prior experiences of caregiving, palliative care may not be transferable to another context, such as home care. This “circular closure of memory” suggests linearity and perhaps that a curriculum cannot arise or transform in a context other than the context in which the curriculum was experienced. This view needs to be balanced with a view that aspects of a preactive curriculum can be translated into practice.

⁷⁰ By circular closure of memory, I mean that a person’s memories around practice may be so deeply engrained that they are not able to be open to new ways of thinking about and learning about practice. The term is taken from Dooley and Kavanagh (2007, p. 67).

A major focus of this phase of reframing memory would be to reposition caregivers who are learning about palliative care and to move their thinking from a decontextualized type of care to thinking about contextualized care.

However, I acknowledge that all memories do not need reframing; for example, traditional healing is buttressed on a communal memory. If we consider that reframing memory is required, then a way to do this may be to introduce ways of thinking associated with interpretivist, critical feminist, post-structural paradigms and participatory action research methods. Thus the caregivers could gain awareness of non-positivist ways of looking at their world.

- **Phase two: Disrupting experience**

This phase would entail palliative caregivers visiting contexts to which they have previously not been exposed. The aim is to disrupt their frame of reference by exposure to diverse contexts and, for example, caregivers could be exposed to a context where they don't know what is causing an illness or how long it is expected that the patient will live. They could also be exposed to a context where no analgesia is available.

- **Phase three: Destabilizing learning**

In this phase caregivers would be required to design palliative care plans.⁷¹ By now caregivers may have thought about differing ways of looking at palliative care, will have had been exposed to unfamiliar contexts, and will be given opportunities to develop palliative care plans which may be discussed. This phase should consider my earlier discussion that sometimes the novice becomes the expert, and vice versa.

- **Phase four: Reconstructing uncertainty**

In this phase context would be factored into palliative care. This palliative care type of curriculum would be based on a premise that teaching about palliative care at a site away from practice (such as was the case in this study) presents an artificial arrangement that may not resemble practising in context.

⁷¹ A care plan outlines the care to be provided to an individual/family/community. It is a set of actions the caregiver intends to implement. It guides an ongoing provision of care and assists in the evaluation of that care.

Teaching at a site away from practice forms an uncertain reconstruction of context. Amin and Ramrathan (2009, p. 75) believe that an important part of this phase is a realization that:

the nature of teaching is unpredictable and that the most important aspect of learning for future teachers is to be prepared for unpredictability and uncertainty.

The thinking around teaching and teachers could in some ways be applied to thinking about caregivers who are finding out about palliative care. In this final phase caregivers could present their understanding of palliative caregiving to a larger group of caregivers who hail from differing contexts, and this phase is the most important as it brings together caregivers' understanding of context and contextual forces in deep, perhaps previously unexplored ways. This phase provides caregivers with a way of looking at and, if possible, dealing with challenges. Caregivers could jointly decide on topics necessary for learning further about palliative care. In this approach to curriculum and training palliative caregivers could thus expect uncertainty in context, their memories could be reframed, and they could look at new ways of facing challenging issues when practising in context. Uncertainty could be welcomed as a potential area for growth and a curriculum would not be expected to provide all answers for all contexts.

11.8 Study conclusion

I opened this study in a critical stance to explore what could happen when a curriculum which was developed in one context was introduced into another context. A post-structural view makes me aware that my own findings and thesis are open to critique, disruption and destabilization.

In a critical stance there is awareness that caregivers and their patients are faced with abject poverty, with little access to healthcare interventions. Caregivers are faced with uncertainty which is not only epistemological. Material uncertainty arises when the patient and caregiver do not know where the next meal will come from. Will the shack stand up against a strong gale? Will the family care for an abandoned child? Will the family provide porridge for their sick relative who lies alone in a darkened shack? Life for a caregiver is *“at best a flowing, changing process in which nothing is fixed”* (Rogers, 1961, p. 27).

Facing death could be regarded as a flowing, changing process in which nothing is fixed. A concept of palliative care developed in the North has relatively recently been introduced to the South. Palliative care can be seen to be a certain response in a certain society. In the North it developed in response to a view that society is death-denying, and offered an attempt to coordinate and plan care. It makes sense that it operates within a medical framework in the North, and it may offer people a way of facing death and a way of familiar caring associated with hospitals and hospices.

In a critical stance palliative care can be regarded as presenting binary opposition or false dichotomies, as it requires a certainty around diagnosis, intervention and prognosis which is not be available in all contexts, particularly in isolated, impoverished rural homes. Palliative care has blossomed in the North and education is a vital cornerstone. Education is underpinned by curriculum and curriculum is grappling with issues around content, pedagogy and purpose.

Although there were challenges in the method, the use of photography and interview as data collection tools enabled me to gain insight into the complex worlds of caregivers who have experienced a preactive curriculum and who practice an interactive curriculum within a society which practices traditional customs and values traditional ways of caring.

Juxtaposing curriculum text with analyses of practice in context has been useful to unearth convergence and divergence between a preactive curriculum and interactive curriculum. Caregivers presented a complex web of uncertainty and certainty, stress, happiness, frustration and fulfilment. The findings from this study, set in a rural area of South Africa, do not represent all caregivers. Palliative care may not present any uncertainty in an urban context, where a caregiver will have access to medical back-up and where patients map onto a medical view of illness, dying and bereavement. A critical stance promotes that the researcher engages in transformation, and after this study I was uncertain around what needed to be transformed.

The development of a curriculum for a complex, multifaceted idea such as palliative care cannot be reduced to a single definition or a narrow, controlled, certain way of looking at the world. Palliative care can be celebrated as open, non-recursive,⁷² complex, multifaceted, and changeable. Gaps between and within a curriculum and a context could be valued as potential sites for emergence of knowledge, rather than as deficits to be filled by positivist thought and associated prescriptive curriculum models. Curriculum designers who focus on methodologies that originate in Northern medical sciences could look at alternative ways of looking at “evidence” which acknowledge both a diversity of ontologies and epistemologies and certainty, uncertainties and complexities of any context.

In the field of education uncertainty has been flagged and foregrounded as important in any educational journey. It is expected that contexts vary and that one curriculum cannot be expected to cover all eventualities, and strategies are put in place to enable a caregiver to expect and deal with or accept uncertainty in context. It depends on the caregiver to make a decision about what to do as there are no set recipes about all that can happen.

I regard palliative care as a safe space in which we can act out our humanity as we engage with people on the margins - and those who are physically ill, mentally ill, handicapped, orphaned, abandoned, abused or dying represent the marginalized of our societies. Society can respond in differing ways to those who are marginalized.

⁷² By recursive, I mean characterized by recurrence and repetition.

An exclusively positivist view of palliative care curriculum may have forgotten that there is a person who lies abandoned in a dirty and darkened shack. Palliative care may have to look well beyond the horizons of health science and “pragmatic evidence” may need to be valued alongside “empirical evidence”. Pragmatism and listening to the voices of those who care in rural homes could be valued as we should not have definitions or certainties outside a context. Palliative care must be careful to avoid a syllogism that placing care predominately within a realm of health science will lead to improvement in suffering. An emphasis on physical care should not subsume care of the idiosyncratic, arbitrary individual. We should not recycle evidence-based concepts and we should not privilege orderly, predictable and certain process in the hope of achieving a stable output. We should struggle through and with our context to make a different future, and palliative care may provide an answer to erasure (see below) and give us an opportunity to remind ourselves of our humanity. An aphorism for palliative care could read simply as an axiom such as “a negotiation aiming to reduce suffering”.

In *Aequanimitas* Sir William Osler (1932) spoke of the ways in which a curriculum can provide guidance, and advocated that a curriculum should consider that to educate the eye to see, the ear to hear and the finger to feel takes time. A curriculum could be viewed as a new beginning, and to start a person off on the right track is all that we can do. We may expect too much of the curriculum and a curriculum should perhaps aim to provide a point of view that will be added to or changed with experience.

Rural caregivers’ voices provided a wealth of information which may be used to guide curriculum designers. Certainty in curriculum may simply be regarded as a point of view which can be changed as our experience of a context grows, and people who are developing curriculum would find it worthwhile to foreground and embrace uncertainty. Certainty could be troubled. However, the point of juxtaposing certainty and uncertainty in rural Africa may be disputed. The tendency in this study was to use an uncertain curriculum as a litmus test for a curriculum in context. The certain/uncertain axis is a variable and may apply to both a curriculum and to a practice at different locations and at different temporal points. An uncertain practice could be researched alongside a certain curriculum. In a post-structuralist vein I conclude my study by calling for future study which considers instances in which the curriculum is uncertain and a practice is certain. The very topic of uncertainty makes conclusions tentative.

This study is an unfinished product, and I remain uncertain around any certainty I may claim around researching or practising palliative care in rural South Africa.

In *Testimony* Felman and Laub (1992) look at surviving victims', perpetrators' and bystanders' ways of responding to the holocaust and the extermination of nine million human beings. They sum up the views of many members of each of these groups as a great conspiracy of silence in which all parties collude, a great cultural secret that we are all keeping from ourselves (Felman & Laub, 1992, p. 14). Felman and Laub use the concept of *erasure* to refer to individuals' failures to perceive, recall and respond with empathy to evidence of inhumane treatment. A study of the holocaust is a study of the worst traits in humanity. I hope that studies in palliative care aim to bring out the best traits in humanity.

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APPENDICES

Appendix A: Permission to conduct research

Appendix B: Acceptance of change of title

RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
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25 FEBRUARY 2010

DR. L CAMPBELL (953059472)
SCHOOL OF EDUCATION STUDIES
EDGEWOOD CAMPUS

Dear Dr. Campbell

PROTOCOL REFERENCE NUMBER: HSS/0079/10D
PROJECT TITLE: "Towards a pedagogy of African Palliative Care: A feminist exploration"

EXPEDITED APPROVAL

This letter serves to notify you that your application in connection with the above has been granted full approval through an expedited review process.

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through the amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol.

Yours faithfully

PROFESSOR STEVEN COLLINGS (CHAIR)
HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc. Supervisor (Dr. Nyna Amin)
cc. Mrs. R Govender & Ms. T Khumalo



23 November 2011

Dr L Campbell
27 Glenridge Road
Westville
3630

Dear Dr Campbell

This serves to inform you that your request for change of title was executively approved and the decision will be ratified at the next Faculty Higher Degrees Committee.

.1	Campbell L	953059472	PhD
	Supervisor:	Dr N Amin	
	Old Title:	<i>Towards a pedagogy of palliative care: A feminist exploration</i>	
	New Title:	<i>Certain the curriculum; uncertain the practice: Palliative care in context</i>	

Yours sincerely,

Nomisa Ndlovu
Postgraduate Studies and Research