

UNCHARTED WATERS – INFLUENCING PRACTICE THROUGH A LIFE
COURSE APPROACH: How caregivers' life experience can influence the care
they give to the elderly at the end of life

by

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ABSTRACT

This project originates from my experience as a Palliative Care Nurse Specialist Educator working from a hospice environment. Observations and collaborative partnerships with staff in Aged Care Facilities provided insight into the palliative care needs of the residents at the end-of-life. Care Assistants (caregivers) provide the majority of direct care and spend most time with residents, with little training for providing that care, to residents with increasingly complex needs.

A two phase exploratory descriptive project was designed using the life course research paradigm and life story narrative research to consider what life experience caregivers brought to their caregiving role in an Aged Care Facility in New Zealand and what influence education had on their work life.

In the first phase a focus group, following education and the implementation of the Liverpool Care Pathway, was conducted and themes identified from an interdisciplinary staff team discussion. In phase two of the project four of the caregivers participated in a life story interview. The thematic analysis of these transcripts provided insight into the four caregivers' life experience. A novel method termed poetic condensation was used in the study to identify the essence of each person's life story. The researcher then reflected on each of the four life stories and identified the turning point in the person's life and a caring moment from the transcript.

The discussion in the thesis reveals the impact of the education sessions and implementation of the Liverpool Care Pathway on the caregivers' practice and how this became a turning point in the delivery of care for the elderly residents particularly those who were dying in the Aged Care Facility.

The researcher concludes the thesis by recognizing that her role as a palliative care clinical nurse specialist and educator is necessary to transfer specialist end-of-life knowledge and mentor staff as they shape best end-of-life practice.

Key Words: Life experiences, health care delivery, aged care end of life, caregiver education, life course narrative

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KEY TO TRANSCRIPTS

Names:	Pseudonyms
Italics:	Participants voice
Chapter headings:	Font 16, lower case, bold type
Sub heading:	Font 14, lower case, italic
Sub sub headings:	Font 12, lower case, italics
Referencing Style:	American Psychological Association (APA)
Caregiver:	Also known as health care assistant, care assistant, care worker

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CHAPTER ONE – INTRODUCTION

Overview

I am a palliative care nurse and have worked in a hospice environment for over twenty five years. I have observed and been an integral part of the growing acceptance of palliative care into mainstream healthcare, in particular over the last ten years. In my current role as a Palliative Care Nurse Specialist Educator (PCNSE) I had a unique opportunity to develop and deliver palliative care education to caregivers who statistically are the main providers of end of life care in aged care facilities (ACF) in New Zealand (Smith, Kerse & Parsons, 2005). Hearing the personal and professional stories of the caregivers in such settings in the region where I am located gave me an insight into the role and how their own life journey enabled them to contribute to quality end-of-life care to residents.

This thesis reports on a project which originated from working as a PCNSE in a hospice. It was my observations and collaborative partnership with colleagues in ACF in the region which have given me further insight into the palliative care needs of the elderly. And more critically how such demanding care impinged on the personal and professional development of the caregivers. I wanted to explore avenues for enhancement of care for the elderly and explore ways to lead regional and national policy and practice development to ensure that the issues I observed could be addressed.

This project I designed uses narrative methodology and the life course research paradigm. I describe the development of education workshops and the implementation of the Liverpool Care Pathway (LCP) in an ACF and explore how this education and mentoring impacted on the lives and work life of the staff in the ACF. The data I gathered from a focus group after the education session began to reveal that the caregivers in particular were most active in providing end of life care to the elderly residents. I had intuitively observed that caregivers have modified their work world to achieve a successful outcome for

residents. Exactly how this occurred was unknown. This realization prompted the development of phase two of the project in which life story interviews were conducted with four caregivers. This contributed to a greater understanding of what happens within relationships between caregivers and residents.

The thesis is structured to allow the reader to follow a series of steps that directed my interest to the topic of the role of caregivers in delivering end-of-life care to the elderly in ACF. The steps in this thesis present a record of how my thinking evolved as I conducted the phases of the project. I consider that this will allow the authenticity of the project to be captured and also offer a record of how an inductive project is shaped.

Chapter One introduces the background to the study, the reasons for my interest and describes my own personal philosophy. I will briefly explain the life course approach that will be referred to throughout this thesis.

Chapter Two describes the history of the modern hospice movement, palliative care and the pivotal position that aged care facilities have in the delivery of palliative care to the elderly. I will then inform the reader of the origins of my role as Palliative Care Nurse Educator. This will be followed by an outline of two key areas of research that informed the study. Education of caregivers and the Liverpool Care Pathway for the Dying.

Chapter Three outlines the chosen methodology for the research as well as the aims, research design, theoretical framework, ethical considerations, recruitment of participants, data collection and analysis.

Chapter Four presents the life story of each of the four caregivers who were interviewed individually.

Chapter Five offers a discussion of the interpretation of the findings focusing on the predominant themes that emerged from the analysis.

Chapter Six summarises the findings of the project and recommendations for development to support and value the role of the caregiver in the provision of end-of-life care in aged care facilities in New Zealand.

Context of the Study

Over the last twenty years there has been a rapid expansion of palliative care services. National and international trends predict an increasingly ageing population, with an increasing proportion of deaths occurring in ACF (Parker & De Bellis, 1999; Froggatt, 2001; Katz, Sidell & Komaromy, 2001; Currow & Hegarty, 2006).

Approximately one third of the dying population is cared for in rest homes and private hospitals in New Zealand (Ministry of Health, 2001). The main emphasis for residents is on maintaining their life. However with the changing profile of the ageing population, older people are entering ACF in an increasingly frail condition with multiple medical problems at a time when they require more intensive care than previously. The nature of the nursing home population is such that residents' health and care needs are fluctuating and dynamic. A significant number of residents die relatively quickly after admission with over 20% within 3 months and 40% over 12 months (Ministry of Health, 2002).

ACF are predominantly staffed with an unregulated workforce of care workers under Registered Nurse supervision. Education and training have been identified as being needed if quality palliative care is to be provided in ACF. The practice development of this group of health workers (caregivers) is often neglected due to funding, resources and workplace culture (Froggatt, 2000).

The role of the caregiver in ACF in New Zealand is a vital role in the care of the elderly and it is of utmost importance that this role is valued, nurtured and given the recognition it deserves. Cain, as cited in Ritchie and Harry (2002) states "it is simply not good enough that many of the most acutely unwell people in our

society can be cared for by workers with no more training than the standard three hour orientation to the job” (p.23).

My role as a PCNSE based in a community and working to liaise from a hospice environment was developed to improve the understanding and application of the principles of palliative care in non-hospice organisations and to provide education, liaison, information and support to health professionals in other settings. International literature suggests that improving the knowledge base of providers will have a positive flow on effect for patients in certain instances (Froggatt, 2001).

The vision I had when first in the role was to use my specialist knowledge to support others in the delivery of palliative care and look at ways as to how to facilitate this. Many ACF have a strong desire to deliver quality ongoing care but are restricted by staffing resources and equipment. Froggatt (2001) comments “education is suggested as a means by which a palliative care approach can be facilitated in all care settings. Education and training have also been identified as being required if palliative care is to be provided in nursing homes” (p.44). This raises many issues. Workforce development is required, particularly where there are skill gaps (Philp, 2002). Caregivers do all the hands-on caring of residents in ACF and are expected to deliver high quality care with little or no training to recognise the signs and symptoms of even basic discomfort. There is much written in the literature that palliative care is not managed as well in ACF as in hospice units (Parker & De Bellis, 1999; Froggatt, 2000; Clarke, 2002).

Froggatt (2000) in her evaluation of a palliative care education project in nursing homes notes that education did have an impact on the care of residents and their relatives in certain instances. However, the extent to which education was able to influence the provision of palliative care within the facilities was limited by organizational factors that were beyond the control of the sessions. Froggatt (2001) also notes that without the involvement of the ACF owners and managers, future developments in this area will be limited and the resources for

funding attendance at courses and covering the cost of releasing staff may not be available. My observations are that nursing homes (ACF) are assuming a slow stream hospice role, particularly for people dying from non-cancer causes.

The New Zealand Palliative Care Strategy states that “All people who are dying and their family and whanau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way (Ministry of Health, 2001 p.vii). A question I ponder is how can this be achieved in an under resourced, under staffed sector of health care and how can we preserve the dignity of the frail, dependant elderly, if we do not value the people who care for them?

This thesis will direct the reader through the stages I progressed through in my role outside of hospice. From the safe confines of hospice palliative care nursing where in some way I had been sheltered from the reality of the ‘real world’, I observed the disparate access to palliative care provision at the end-of-life in ACF. I also observed the hard, heavy, unsung work of the caregiver. The findings in this project highlight that it is critical to acknowledge the importance of the compassionate care given to the elderly at the end-of-life. This study reveals how educational opportunities and ideas shared through story telling life stories have the potential to reveal the true value of the caregiver role.

As the nurse or caregiver guides the patients and families through their illness, I want to guide the reader through the stages of my own vision which was literally “unchartered waters”. At the outset as I stepped outside of the hospice environment and into the aged care sector environment, I was confronted to some extent by issues as they arose. This thesis presents phase one and two of the research project as collegial collaboration took place.

Researchers Interest

To understand more fully why the care of some of the most vulnerable dependant elderly people, with multiple co-morbidities, is entrusted to an unregulated, untrained workforce, I proceeded to find out from the caregivers themselves what their own life experience brought into the role. This occurred initially in conversation across facilities and then in greater depth in a focus group and finally in great detail with four caregivers being interviewed. I was also interested to find out if the education received influenced their own well-being thus improving the quality of care delivered to the residents at the end-of-life. Ultimately I was interested to know, what the funders and planners of health care need to know when considering future plans for the development of the aged care workforce in the future. I wanted to conduct research that might support their vision.

I practiced at a high level within a multidisciplinary team in a hospice environment and had the privilege to be supported as a specialist nurse through ongoing education. I had always been given personal support and had resources made available to me for my own well-being. The hospice philosophy was to care for staff as well as for patients and families. The evidence of the worth of this practice philosophy was extremely low staff turnover and the development of expertise in the community

The main feature and joy of my nursing was in direct holistic patient care which meant total hands-on care. My observations in ACF was that most of the care at end-of-life is given by caregivers who are an unregulated workforce, often with little education, training or support. The people they were caring for required the same care as those dying in a hospice and yet there was no equality in the level of palliative care delivered. These comments are in no way critical of the incredible people who do the caring. In fact, the opposite. The care and concern for the elderly I observed from the experienced caregivers was superb. The registered nurses role was to oversee this group of healthcare workers but often

the registered nurse time was taken up with medications dispensing, arranging staff, trying to access after-hours medical care or arranging resident admissions to hospital. No matter how we look at it, one nurse for a large number of residents is not feasible.

These initial observations in the new role kept returning me to my question: who provides the care in an ACF to the elderly person who is dying? I had to acknowledge the answer was the caregivers. If I was to impart knowledge and make a contribution to the elderly in our society, these were the people I should establish relationships with and support. After developing education sessions and implementing the LCP within an ACF I created relationships and informal partnerships through mentoring caregivers and by asking “how are things going?”. Initially the caregiver would talk about how busy they were, about lack of staff and staff not turning up and I noted that they always spoke about someone who was ‘not so well’. Eventually, they would be proud to inform me that they had sat with a dying patient and then proceed to tell me of ‘the little things’ that they had done. The increased confidence to share demonstrated that they had put learning from our sessions into practice. Thus, the casual conversations and spontaneous sharing of information was having an influence on the quality of care given to the elderly at the end-of-life. Documenting exactly what was occurring became the important focus for my research. My first inclination was to go back to my own experience of education and training and how turning points had happened for me to alert myself to become more attuned to listening to caregivers.

Life Story and Personal Philosophy

In this statement of personal philosophy I link my beliefs and life story journey to my philosophy of care. Although currently indirectly involved with patient care, I can uphold my philosophy in practice by supporting, mentoring, educating and enabling those who do the daily care. I take this opportunity to articulate my

philosophical position to nurse managers and care givers as I introduce myself, my life story and beliefs and I reveal how the palliative care philosophy shapes my philosophy and practice. I indicate that being articulate both invites and gives me the mandate to speak as a colleague and a professional.

I reveal in my life story narrative that I am a graduate of a hospital based training school from the class of 1966 and describe myself as a practical person with a “hands-on” ability which was a product of training in that era. My love of years of hands-on bedside nursing has made me never want to lose touch with the reality of the demands on nurses working at the bedside. I believe that theory must always relate to practice and my aim is to not create frustrations for colleagues through making impractical goals or even impossible demands. I indicate that my interest is in investigating how a nurse or caregiver thinks about care, and how their practice is framed by deep thinking based on reflecting on their experiences and not by just reading manuals.

I state that I have worked for over twenty five years in the specialty of palliative care within a hospice. Palliative care nursing has given me many opportunities and I have never been in any doubt as to what nursing is. The care and comfort of the patient has always been paramount. I recount that I believe I am a patient advocate and my passion is dignity and patient autonomy in palliative care.

The essence of my nursing practice as a palliative care nurse is “being with” patients, family and whanau. The value of presence and calmness was something I always felt important in the early days of my nursing and over the years of gaining experience and knowledge I have been able to further develop my skills in this area. To presence oneself with another means that you are available to understand and be with someone (Benner & Wrubel, 1989).

My own philosophy of nursing is predominantly one of caring, which ultimately maintains dignity and autonomy for the people I care for. If the concern or intent to care is not present, the personhood is not acknowledged so the care will be incomplete. I am drawn to the writings of an experienced nurse-educator, Sister

Simone Roach (2002) and her interpretation of caring. Her view is that “caring is the human mode of being” and “the most common authentic criterion of humanness”. I support her argument that caring is not unique to any one health care profession but rather is an important component of each one (1997). As a nurse educator, I see and hear many moments of care expressed by caregivers that are instinctive and intuitive. My role as nurse educator now permits me to influence care by sharing my own philosophy and also the teachings of Roach (2002). She describes the five “C”s, which she proposes all authentic caring responses must include: compassion, competence, confidence, conscience and commitment. The caregivers in these sessions in turn share their thoughts and their own life stories and values that demonstrate care. Kenny (2003) believes that nursing requires practitioners to care for and be responsive to other human beings. I support this belief as it shapes my own practice and one I would hope to convey as extremely significant when educating caregivers.

The life course is framed from the moment of birth, with experiences that shape us as to how we will respond and react to situations. My experiences and stories of nursing have enabled me to direct the caring part of myself to connect with others. My life from birth up to the present time has shaped me into who I am. This also applies to the people I care for and educate. We all have many “hats” formed from life events and life experience which we bring when connecting with others.

One of the turning points for me in my own nursing career was postgraduate nursing study. It changed the direction of my nursing career into the area of education. My own postgraduate studies endorsed and strengthened my knowledge base and enabled me to disseminate palliative care knowledge to areas of practice outside of hospice. It is with renewed passion that I now advocate for my colleagues in the aged care sector. It was from this view, when I was exposed to the delivery of palliative care outside the confines of hospice, I witnessed an area where the skill mix of staff influenced how quality palliative end-of-life care would be delivered. It caused me to think what was the

“specialist” knowledge in palliative care. I used the life course framework to frame my interests as follows: Families throughout history have always cared for those dying. People have died and been cared for by untrained, unskilled (in the nursing context) family members. So what does unskilled mean in this context? How is anyone trained in “caring” at the end stage of someone’s life? What role has the unregulated caregiver working in an ACF in the care of the dying? What do they bring to the role from their own life experience? This is what I was interested in exploring. I know that some ‘caring moments’ seem to be currently inhibited and that caregivers work advocated the direct care I value.

McKinlay (1998) stated “As my professional clinical practice developed, I learned that the ‘real work’ of nursing is not in the undertaking of technical tasks, but the human interaction that occurs alongside, within, or after the moments these were completed” (p.4). It is these moments that fascinate me and they will be revealed in this project especially through the caregivers own stories. The interviews I conducted with caregivers gave me insights into the little things and moments of care given to the elderly at the end-of-life; these moments had to somehow be presented in a way that had meaning and value. I heard the caregivers’ stories, the intonation of their voice and witnessed their body language as they spoke and revealed these moments. I had to find a way that epitomised the true essence of what I heard, saw and felt.

In this section I have invited the reader into my own personal space. The next section will give an overview of the life course and how this relates to the caregiver. This introduces the theoretical basis that framed the project.

Life-Course

This project is informed by life course research concepts and life story concepts in narrative inquiry. Daaleman and Elder (2007) state that life course principles direct attention to individual choice and decision making, endorse an awareness

of larger social and historical contexts and promote an understanding of the timing of events and role change. They also view human lives within a matrix of relationships with significant others. Life course principles guide inquiry by enabling a holistic understanding of lives over time and across changing social contexts.

“The life course perspective which arose from a confluence of movements in sociology and psychology in the 1960s subsequently came to involve economists, anthropologists, historians and others. It looks at the distinctive series of roles and experiences through which the individual passes as she or he ages from birth to death and inquires into the impact of various changes on these patterns” (Kertzer, 1986).

Life course ideas focus on the changing contexts of lives and their consequences for human development and aging (Elder & Johnson, 2000). I have come to understand the value of the early life-course models in which I was trained. Research identified the distinctive series of roles and experiences which an individual passes as she or he ages from birth to death and inquires into the impact of various changes on these patterns (Kertzer, 1986). The principle of lifelong development and aging embraces an intergenerational perspective that links early life influence with events and outcomes in subsequent years. For this project, the life story of the caregivers and their life experience was of interest as it could have a direct bearing on the way they cared for the elderly at the end-of-life.

The life course of individuals is structured by social influence and the life choices people make in constrained situations. A more accurate definition is that life course is a paradigm that views people in context over time. It provides an understanding of individual people by examining events and experiences over a life span (Daaleman & Elder, 2007). It looks at their life experience and how that influences and shapes the way they make choices. From my observations the intuitive caring practiced by some caregivers demonstrated

that this practice came from within and was based in an instinctive knowing of how to care for another vulnerable person.

Daaleman and Elder (2007) offer physicians' assumptions about life course and a conceptual framework. This views people in context over time as professionals seek to understand individual patients within the context of their families and larger social environments especially when they make choices for health and well being. I think it is an outstanding framework and I have made suggestions below for how it could be adapted to nurse and caregiver practice where the focus is on the person's whole life story.

The Daaleman & Elder Framework (2007).

The Paradigm

The life course theory offers a paradigmatic grounding to family medicine, a discipline that is attempting to understand contextual factors using concepts outlined in Table One. Life course thinking relates the tradition of family physicians who provide care within the context of their communities; as a process in which physicians develop a life history of their patients over time and across the generations. A nursing version of this framework may read as follows:

Life course theory revisited could offer a more grounded approach to care of the elderly. While the focus is on one era of the life journey the whole of a persons life story is relevant.

The Philosophy

At a philosophical level, life course theorizing fixes the clinical gaze of family physicians beyond the patient as member of a family unit to the patient who is a traveler on a journey along their life course. This suggests a role for the family physician as patient historian and interpreter, and health care guide and

advocate along the trajectories, transitions and turning points that accompany health and illness.

Life course revisited in the elder care setting at a philosophical level fixes the clinical gaze of the caregiver to be the listener of the person's life story. The person who holds their being and soul story intact.

The Practice

Life course principles would direct the physician's attention to the contextual factors that affect patient's choices, plans and initiatives regarding their health and health care. Facilitating life course choice making in practice settings is an art and a skill which caregivers explore and develop as they engage with elderly people

It is these life course principles that Daaleman and Elder suggest could direct the physician's attention to individual choice and decision making. My question was what would direct nursing attention to promote an understanding of the timing of events and role change. Based on this I then looked closely at their conceptual framework in Table One and identified several points as follows. Choices about health and well being are considered to be what determines our life course. Identifying the changes a person makes made sense in the eldercare context. Transitions or changes in the life course are referred to as 'turning points'. These are individual or institutional sentinel moments that result in a change of direction in one's life course (Daaleman & Elder, 2007). The caregivers I observed, educated and interviewed revealed to me their understanding of the significance of life experience knowledge they used to create a caring environment. Life course theoretical concepts such as turning points created a new horizon. Each knowledge form had equal value and one enhanced the other. The education given acknowledged the life experience and gave confidence to the ongoing learning.

Table 1. Organising Concepts and Principles in the Life Course

Term	Definition
Trajectory	Sequences or long-term patterns within a focal area (e.g., health, family, or work situations) that are imbedded in social pathways and defined by social institutions.
Transition	Changes in state that are discrete, acquire meaning within trajectories, and have an identifiable beginning and end.
Turning point	Individual or institutional sentinel moments that result in a change of direction along one's life course.
Linked lives	The interdependence and network of shared relationships that surround individual lives.
Social convoy	A grouping of significant others (e.g., important family members, long-time friends) across different life periods.
Timing	The developmental antecedents and consequences of behavior patterns, life events, and transitions that vary according to their chronological location in a person's life.
Human agency	Views people as active participants who construct their own life courses through the choices and actions they take, given the opportunities and constraints of history and social circumstances.

Daaleman and Elder (2007).

CHAPTER TWO – STEPPING OUT

This chapter will give a brief history of the hospice movement and the emergence of palliative care as an essential component of all health care. It is extremely relevant to position this here as care of the dying in modern society was challenged by visionaries who saw that there was a ‘better way’ to care at that time. I will follow this discussion with how my role was positioned to disseminate the principles of palliative care through education and the implementation of the Liverpool Care Pathway into an ACF.

Hospice Philosophy

Throughout history care for the dying has evolved in all cultures in a myriad of ways to comfort patients and the bereaved. In the middle ages, hospices provided shelter for ill and weary travelers who often died along the way. Later, monasteries and nunneries cared for the terminally ill, regarding them as pilgrims en route to a state of peace. The word Hospice comes from the Latin word ‘hospes’ meaning a host, hospitality; to host a guest or stranger. The modern hospice is a relatively recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher’s Hospice in 1967. It was founded by Dame Cicely Saunders, widely regarded as the founder of the modern hospice movement. Her belief that dying is a phenomenon "as natural as being born" was at the heart of a philosophy that sees death as a process that should be life-affirming and free of pain (Cook, 2005).

Saunders (1996) introduced the idea of "total pain," which included the physical, emotional, social, and spiritual dimensions of distress (Richmond, 2005). Crucially, total pain was tied to a sense of narrative and biography, emphasizing the importance of listening to the patient’s story and of understanding the experience of suffering in a multifaceted way (Clark, 2002). She regarded each

person, whether patient or staff, as an individual to the end. A good listener, she paid systematic attention to patient narratives. One patient she cared for was David Tasma, a forty year old survivor of the Warsaw ghetto (Cook, 2005). He was dying of cancer and she was his only visitor, and as the two became close they talked about the care patients need at the end of their life. In my experience it is the person at the bedside that hears the narratives of people they are caring for. In the present day, caregivers are the people most likely to hear the stories whilst tending to dying residents. Saunders as cited in du Boulay (1984) endorses this in her comment “Those dying need the friendship of the heart, with its compassion, acceptance, and reciprocity. They also need the skills of the mind, embodied in competent medical care. Neither alone is sufficient” (p.23).

I utilize these ideas about the history of hospice when sharing my own philosophy of care with caregivers and this sets the scene for narrating stories of people like them who care for dying people. Sharing Tasma’s narrative encourages caregivers’ to share resident’s stories as well as their own. I then describe how I think her practice changed. I indicate when teaching how this insight with Tasma became the turning point which changed the direction of her life.

Her story of care changed the way people who were dying were cared for internationally. Saunders (1984) emphatically stated that education is the means to understanding what is required and to develop a capacity to recognize that each person is unique. Caregivers themselves are in a unique position to assess and interpret the person’s situation in order to provide the kind of care Saunders advocated. When I introduce the history and philosophy of hospice care to caregivers, they are always touched by the simple story of the beginnings and after sharing stories and discussion they come to the realisation that they too have the power to make a difference. They always ask for more information on Saunders as the story resonates with most of them as they can relate back to a memory or situation in their own life, which was a turning point

and has become recognized as potent learning through a lived experience. The caregivers discover that they recognize the reflective message in this quote by Saunders who identifies the heart of palliative care (as cited in Cook, 2005).

"I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, 'For someone to look as if they are trying to understand me'," she said. "Indeed, it is impossible to understand fully another person, but I never forgot that he did not ask for success but only that someone should care enough to try." (p.1).

I relate how when planning St Christopher's Hospice Saunders stated "The name 'hospice' a resting place for travelers or pilgrims was chosen because this will be something between a hospital and a home, with the skills of one and the hospitality, warmth and the time of the other". This statement could not be more fitting when considering the care of the elderly at the end of life in an ACF. Many elderly live in ACF until they die so therefore play an important part in the overall provision of care for dying people. While hospitality is a new concept for caregivers they immediately recognize its value as they respond to residents in every day in their care

Local Context

The hospice philosophy and movement has extended across the world and also exists in New Zealand. Marion Cooper, who founded Te Omanga Hospice, set out to improve the quality of terminal and palliative care in New Zealand.

"I guess nothing really ever starts with one person" says Marion Cooper (2004) carefully, but those involved with the Te Omanga Hospice project tend to point to Marion, who recognized the need and was willing to do something about it. Marion's interest grew from her personal experience.

“I sat beside the bedside of a nursing colleague and a very dear friend who, after a six month battle with cancer was dying. At her greatest hour of need and after a gallant fight I could not remove her pain nor help her with a peaceful and dignified death” (Cooper, 2004).

Marion made a decision and this sentinel moment in her life changed the course of her own life and directed attention locally and nationally to the lack of provision of quality care to people who were dying at that time. On the basis of her personal experience she, like Dame Cicely Saunders, embraced the hospice philosophy and was instrumental in providing a new dimension to care of the terminally ill in New Zealand.

Caregivers have similar stories to tell about people they care for and their life experience often encompasses the same philosophies as portrayed by the hospice founders.

This section has sought to inform the reader of the beginnings of hospice and to appreciate the significant contribution made by the visionaries of the time who changed the direction of care given by making choices in their own life course. Their courage and dedication have changed the face of dying across the world. Over time, with the increasing acceptance of this holistic model of care as an essential component of all health care the term palliative care was born. The next section describes the principles of palliative care.

Palliative Care

Palliative care is the active care of people who are living with and dying from active, progressive diseases and other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of well-being – tinana, whanau, hinengaro and wairua - and enhances a person’s quality of life while they are dying. Palliative care also supports the bereaved family and whanau (Ministry of Health, 2001).

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

The New Zealand Palliative Care Strategy (2001) identified the importance of equitable access to palliative care for all New Zealanders regardless of disease or place of residence. Traditionally, palliative care had been associated with the care of people with cancer but the principles of palliative care are applicable for all people with a life threatening illness.

Palliative care provision in New Zealand has improved dramatically over the past 25 years. One of the more recent struggles and a major focus of the New Zealand Palliative Care Strategy (Ministry of Health, 2001) has been to disseminate this same level of quality care to all those who need it, regardless of their diagnosis (cancer or other), location and available resources. It was to honour the intent of this strategy that my interest was directed to the provision of palliative care in ACF.

Aged Care Facilities

The previous section described the history and emergence of hospice and palliative care and the recognition and acceptance that palliative care principles should be a component of all healthcare settings. This section will consider ACF and discuss why I am interested in investigating the role of the caregiver in providing care to the elderly at the end-of-life. Education in hospice palliative care and the role of the PCNSE will be described.

Providing palliative care to residents of ACF is an ever increasing need internationally within health services. As mentioned earlier, for the group of people most likely to die (the very elderly), care before death tends to be given

within residential and nursing homes (Clarke & Seymour, 1999; Wowchuk, McClement and Bond, 2006; Hodgson and Lehning, 2008). In New Zealand these homes are referred to as aged care facilities (ACF) and there has been a proliferation in the number of ACF over the last ten years. ACF play an important part in the overall provision of palliative care for dying people (Avis, Jackson, Cox & Miskella, 1999) yet often do not have the resources to provide that care. Since national and international trends predict an increasingly ageing population, with larger proportion of deaths occurring in ACF (Parker & De Bellis, 1999; Froggatt, 2001; Komaromy, Sidell & Katz, 2000) the number of people in ACF will rise exponentially. In New Zealand 13 percent of the population will be over the age of 65 by 2010, rising to 25 percent by 2051). It is estimated that currently 28,000 adults over the age of 65 years are in residential care in New Zealand (Smith et al., 2005).

Based on my local area using this criteria the majority of people designated palliative care out of this group would qualify for palliative care. Identifying this number is important since development of workforce requires funding and strategic planning. Long term planning for staffing needs is critical and planning for their education essential. It has been my observation over the last five years, and supported by the literature (Eyres & Bryan, 2006; Currow & Hegarty, 2006) that the complexity of care has increased and ultimately the increased severity of illness of residents will drastically affect the care that is provided by staff. Whilst hospices had predominantly cared for people with a malignant disease, many elderly people with a life-threatening illness have a complex chronic disease and a more unpredictable trajectory. This group of people often end their days in an ACF at a time when their health needs require more intensive care than these facilities currently provide. More people from with non-cancer diagnoses are referred to hospice services than ever before. This is seen in the percentage of referrals to hospice services which has increased on an average of 20-25% yearly. When I first began supporting and collaborating with the ACF in my local area the percentage was 9%. The referrals are now approximately 30% which indicates why there is an increasing need to provide palliative care

education to ACF and why resourcing of education staff needed. Nationally, this was reported by other colleagues and to address the increasing need for palliative care in ACF, the Ministry of Health developed the Care of the Older People Strategy (2002). In this Strategy the objectives clearly stated that most recipients of palliative care are older people and that staff in ACF have an understanding of the palliative care. The policy objectives that were developed to guide practice are listed below.

Objective 8 in this strategy stated: Older people with high and complex health and disability support needs will have access to flexible, timely and co-ordinated services and living options that take account of family and whanau carer needs. (p.57). Furthermore:

Section 8.4 referred to 'Implementing the Palliative Care Strategy'. The Palliative Care Strategy recommends that palliative care should generally be available to people whose death from progressive disease is likely within 12 months (Minister of Health 2001). Most recipients of palliative care are older people. For some, the need for palliative care comes at the end of a progressive disease, which has required long-term, often high level and complex care (p.61).

Section 8.4.1. The Ministry of Health and DHBs will undertake work to determine appropriate service provision to ensure that people receiving long-term care have access to essential services set out in the Palliative Care Strategy when they need them. This requires that:

- Staff in long-term care services have an understanding of the palliative care approach to alleviating pain and other distressing symptoms, and/or provide support during the last months of life
- There is a seamless transition for people who need palliative care services (p.61).

In my role I was increasingly disturbed by the expectation placed on the managers and staff working in ACF. I have used these policies to illustrate that

the written word and requirements of such strategies do not take into account the nature of the work. Broad statements within policies appeared to me to pay 'lip service' without addressing workforce issues, and especially did not indicate provision for funded education to be made available. I visited many ACF where I observed the inequity of care, compared to hospice care, not through the lack of intent by the aged care workers but by the sheer physical impossibility of providing holistic end-of-life care to the Gold Standard Framework (Thomas, 2003) as delivered by hospices.

When I recalled nursing in the sixties most of the people with multiple medical problems were cared for in the public system. My nursing colleagues from that time well remember the geriatric wards in the local hospital. Patients were cared for, sometimes for many years in these wards with care provided by trainee nurses, registered nurses with access to medical cover twenty four hours a day and access to medications as required. It made me ponder on the fact that in this era of nursing advancement, had nursing moved so far away from the essence of nursing and caring that we now entrusted the care of the elderly to unregulated healthcare workers?

ACF are currently likely to be providing palliative care and be more involved with terminal care. ACF have been forced to assume greater responsibility for dying persons, with the additional demands for supportive and medical care which this entails (Maddocks & Parker, 2001). In New Zealand, concern has also been expressed about the increasing use of "untrained and unregulated caregivers in nursing homes (Bland, 2004).

It has been acknowledged that ACF have steadily become a more common place for people to live out their lives until death. The main emphasis for residents has been on maintaining life but with the changing profile of the ageing population, older people are entering aged care facilities in an increasingly frail condition with multiple medical problems at a time when they require more intensive care than previously (Kristjanson, Walton & Toye, 2005).

What is of greater concern to me is that poor quality nursing home care is a persistent concern (Arling, Kane, Mueller, Berchadsky & Degenholtz, 2007). In a recent study to determine the relationship between nursing home staffing level and care received by individual residents, Arling et al., reported that staff skill mix (i.e., proportion registered nurse to caregiver) to be an important factor in quality. In other studies it was argued that nursing homes rely almost exclusively on the common sense of unqualified staff that is unlikely to receive any training in meeting the needs of dying people (Avis et.al.1999).

This issue of education clearly needs to be addressed at a national level. During my associations with caregivers I was most impressed and interested with the work of the caregiver. The commitment I observed with the group I was involved with made me think of how I as a trainee nurse was trained and worked under the watchful eye of nursing tutors, charge nurses and supervisors. A military style overview of practice and care was observed and assessed. Times have changed but caregivers do the role that nurses did many years ago without the basic training and mentoring into the role.

Hammond (2001) states, "there are in reality many significant contextual differences between a hospice and an aged care complex. These relate to resourcing, education and qualifications of staff, relationships among staff, and medical condition of patients (p.24). Overall, there is generally a lack of acknowledgement within the health care sector and the general community, as seen in the literature, of the complexity of knowledge and skills required for the effective and appropriate nursing of older people. This lack of recognition of expertise serves to devalue the role and thus, render aged care nursing a low status pursuit (Australian Government Department of Health and Ageing, 2004).

Education and training have been identified as needed if palliative care is to be provided in ACF. Froggatt (2000) in her evaluation of a palliative care education project in nursing homes notes that education in ACF did have an impact on the care of residents and their relatives.

Quality of care of residents in ACF is an issue that has been highlighted more recently in New Zealand due to reported cases of elder abuse. Although we must put this in context of the excellent care provided by many, we cannot ignore the increasing burden placed on the staff in ACF to provide quality care but without the resources necessary for this.

The project went through uncharted waters many times but I was inspired by the principles of palliative care and by the visionaries who did make a difference to the care of the dying. Visionaries Dame Cicely and Marion Cooper, had stepped out of their comfort zone and identified how health professionals could make a difference as they cared for the dying. I reconciled that they too had been concerned and driven by what they had observed and experienced in the care of dying people. They had challenged the impersonal, institutionalized approach which was common in caring for the dying especially in hospital settings. Respect, compassion and dignity were hallmarks of their vision. Apart from the scientific approach to effective pain management that Saunders introduced with great success, she introduced the concept of “total pain” which included the physical, emotional, social and spiritual dimensions of distress. Being a good listener, she had paid attention to patient’s narratives and it was from listening to such stories that she was able to establish the palliative care model of holistic care. Bradshaw (1996) also notes that the nursing care ethic greatly impacts on end-of-life care. I could not help but bear these points in mind when I observed who was delivering the care and reflected on the caregivers work life stories.

In a small way I was guided by their vision to step out of my comfort zone and confront areas of concern. Care of the dying was again being re-evaluated as society changed and medical technology advanced to another level with the goal of achieving a cure. People today are living longer with more chronic co-morbidities diseases and the most common place for the elderly to be cared for at the end-of-life are within aged care facilities. The caregivers in such settings were now the main providers of care for such people. By collaborating with

aged care colleagues I considered that together we could make a difference to the quality of care of the dying elderly.

This section on the context of palliative care embodies why there is a need to explore the role of the caregiver and their understanding of the vital role they have in the care of the elderly at the end-of-life. The next section will describe the role of PCNSE and how this role developed to meet some of the identified gaps in the delivery of palliative care.

The Project begins - Palliative Care Nurse Specialist Educator

In 2002, the local District Health Board and the local hospice entered into a partnership to meet their commitment to the New Zealand Palliative Care Strategy (Minister of Health, 2001). The New Zealand Palliative Care Strategy recognised palliative care as a legitimate component of health care and there was an increasing awareness that people with non-malignant diseases could benefit from palliative care. The overall goal was to improve the integration of palliative care with other health services and to increase health professionals understanding and application of the principles of palliative care. The Strategy also identified the importance of equitable access to palliative care for all New Zealanders, regardless of disease or place of residence. It also identified a lack of awareness among Maori. It was anticipated that the benefits of increased awareness of palliative care would improve the care of patients, wherever they may be, in the end stage of their life.

To honour the intent of the Palliative Care Strategy, the Palliative Care Nurse Specialist Educator (PCNSE) role arose out of a multi-party workshop identifying a perceived gap in the provision of quality palliative care in the region. The service was designed to support health professionals working in non-hospice organisations and to support ACF in the palliative care needs of the residents through education and liaison. The PCNSE role aimed to improve

integration of palliative care with other health services which would ultimately impact on the quality of care for people who are dying and their families and whanau.

In the initial stages, it was important for me to develop relationships and trust with the ACF and other health professionals. This took some time, but the result of the collaborative approach I developed with the health providers enhanced the care delivered to the patients requiring palliative care. I visited all ACF, General practices, Iwi Groups, Pacific Health, Primary Health Organisations, Medical Peer Support meetings and Specialist Nurses and acknowledged the expertise already held in each speciality.

Palliative care education was the catalyst to change. In the next section I will describe the how education workshops for care givers were developed and delivered to caregivers and how that impacted on their own well-being.

Development of Education Sessions for Caregivers

This section continues the journey with caregivers as they were introduced to palliative care education sessions for the first time. It will capture how a different approach to learning revealed insights into how caregivers responded to learning within a caring environment.

As stated earlier, I had established relationships with the ACF in the local area and offered palliative care education sessions on site to meet with staff and introduce them to the principles of palliative care. I was receiving more and more requests for education sessions and was developing sessions as and when requested. Roles similar to mine were developing in New Zealand and it seemed sensible to meet together, and review the content of education sessions being offered and share resources. In 2004, a group of hospice educators met to discuss the development of a national course and seek support from the national organization, Hospice New Zealand. Several

members of the group were co-opted onto the Hospice New Zealand Education Advisory Committee and the end result was the establishment of an education programme designed to provide caregivers with key principles, practical knowledge and skills of palliative care. The purpose of the course is to enable care givers to deliver improved palliative care to their patients. This course has been designed specifically to meet the needs of care givers (unqualified staff) working in ACF. One of the strengths of the course is that it is only for caregivers and it values the contribution they make to the care of the patient, family and whanau. It is highly interactive and participants need to feel comfortable enough to join in with the activities and discussions and share their experiences (Hospice New Zealand, 2005).

To facilitate the new education programme the principles of adult learning were applied. It was acknowledged that adults bring a wide variety of life experience with them to class, vary in their physical and mental abilities, including their reading ability, hearing, dexterity and concentration and vary in cultural background and in ways they learn most effectively. Many adults have had negative experiences at school and so lack self-confidence in a learning situation and prior knowledge, experience and reasons for enrolling will vary among students in the same class (Whitireia Adult Learning, 2001).

Jarvis (as cited in Ward and McCormack, 2000) suggests that to construct a theory of adult learning the socio-cultural background of the individual must be taken into consideration; hence the unique nature of those involved in the learning process is taken into account. From my experience as an educator, I believe it is also important that students of all levels have the capacity to learn new knowledge if it is presented in a meaningful way and if teachers provide the needed support to help students make meaning of the learning. Many of the caregivers I had met had little formal education and it was important that I encourage and create a non threatening environment for them.

Locally one hundred caregivers attended the palliative care for care assistant's course in the first year. They are initially welcomed and thanked for the valuable contribution they make in the care of the elderly. The environment is welcoming and warm with music, flowers, food and drink. Most have come from a busy morning at work or have come on a day off to attend. The atmosphere is created to be nurturing and caring. The purpose is to show the students that they bring a wealth of experience with them and their knowledge is valued. Nursing, as a profession, has observed that a caring relationship from which evolves concern, connectedness, presencing and respect for autonomy is vital if we truly want to care for the whole person. In this teaching environment, caring was the key. The caregivers were open to this way of learning and I was eager to capture their attention and hold it.

This caring relationship is as important between educator and student as it is to nurse and patient. Benner's model focuses on the skills of caring. Benner (1984) talks of "caring" as a word for being connected and having things matter works well because it fuses thought, feeling and action-knowing and being" (p.). If the concern or intent to care is not present, the personhood is not acknowledged so the care will be incomplete. I found this theory worked well with the caregivers as the more they felt valued the more they shared. Davies and Oberle (1990) identified six dimensions of the supportive role of the nurse in palliative care: Valuing, connecting, empowering, doing for, finding meaning and preserving own dignity. These can also be concepts for the educator to convey knowledge to the caregivers. Baker and Diekelmann (1994) also identified narrative as an effective tool in facilitating education and storytelling is promoted as being integral to the knowledge, learning and reflective practice of nurses.

Nurses have always shared stories. In my experience in the nursing homes when junior nurses listened intently to the experiences of their colleagues they felt safe sharing their own experiences. They were reflecting on not only their practice but that of their friends. Much learning took place in this environment.

The care givers had the same stories to tell but often did not have the opportunity or place to tell them and reflect back on them. Also the culture of the workplace, multi cultural mix of staff and lack of confidence of caregivers were barriers. We learn from experiences and sharing experiences is a way of educating and affirming what may work. Johns (1995) states that “the essential purpose of reflective practice is to enable the practitioner to access, understand and learn through, his or her lived experiences” (p.226).

Clinical storytelling is a powerful tool in assisting the listener and the storyteller to develop shared knowledge and a greater understanding of the culture of nursing practice (Moss, 1993). By telling of the everyday experience in an aged care facility, the caregivers began to connect with each other and have an understanding of how and why they did things a certain way or conversely a different way with the same result. Experiences shape us as to how we will respond and react to situations. Stories of nursing enables us to direct the caring part of ourselves to connect with others. Life from birth up to the present time shapes us into who we are. We all have many “hats” of life experience we bring when connecting with others and the life course of the caregivers impacted on how they perceived and valued themselves.

As the weeks progressed students became more comfortable with the informal environment and shared their experiences more freely. The inclusive teaching style enabled the educator to, as noted in Ironside (2006) “attend to teaching the practices of learning and thinking as well as teaching content” (p.484). As stories unfolded a sense of understanding and connectedness was shared. Some students expressed their distress at not knowing what to do or say, especially when patients were dying. Kenny (2003) discusses how using Edward de Bono’s six hats game on reflection enabled them to see they had made a difference. The six thinking hats game was devised by de Bono to help people think more effectively. The more in depth discussions about how they felt at the time and how they would do it differently ensued. The facilitator was able to identify areas that needed more reflection and used personal

experiences to illustrate ways of practice. Other students shared how they managed the same situation. A supportive environment was evolving. Johns (1998) reports “having told her story the practitioner is encouraged to identify what is significant within the story” (p.4).

Students were eager to have time to tell their story as the environment was affirming and supportive. Practices within facilities were discussed and positive practices when death occurred were exchanged and implemented with pride. The educator shared narratives as expert practitioner and these stories were affirming for the students who could relate similar situations and express an increased understanding. The primary goal of any educational program in health care is to professionalise the human capacity to care through the acquisition of knowledge and skills (Roach, 1987). The education sessions initiated an increase in the caregivers own well-being as they felt acknowledged and listened to.

The not knowing became the knowing. The mundane tasks of everyday care took on a new meaning. The simple act of giving a patient a wash and how this essential rather than basic act, could create a sense of care and compassion. Lewis (1998) states that learning in the nursing context is seen very much in the light of doing, where experience is often profound and unique.

Benner and Wrubel (1989) talk of “caring” as a word for being connected and having things that matter works well because it fuses thought, feeling and action-knowing and being”. Nursing, as a profession, has observed that a caring relationship from which evolves concern, connectedness, presencing and respect for autonomy is vital if we truly want to care for the whole person. Caregivers are directly involved in the day to day care of the residents when they are dying and are often in a prime position to discuss residents’ feelings and fears.

Caregivers were “hungry” for more knowledge. They felt that some aspects of their new knowledge would not be allowed to be incorporated into their facility.

Froggatt (2000) states that before any future educational courses in palliative care are developed to influence the care of residents dying in nursing homes a greater understanding of the nursing home culture of care is required (p.146). Discussion around how the new learning could be incorporated into practice was beneficial.

Caregivers derived great pleasure and felt good about themselves and the work they did when the course was completed. They felt valued and nurtured in a caring environment and felt listened to in the telling of their stories. Boykin and Schoenhofer (2001, p.1) state that “caring is an essential feature and expression of being human and that caring is a process”. According to Ernestine Wiedenbach (as cited in Bennett and Coldwell-Foster, 1985) “nursing is nurturing and caring for someone in a motherly fashion. That care is given in the immediate present and can be given by any caring person”. This section has described how education sessions were developed and implemented for caregivers. The use of narrative was used as a tool to assist in supporting staff to value the work that they do. Evaluations confirmed that caregivers increased confidence did have an effect on their own well-being as they were now aware of the value of their work. The next section channels this new learning into the internationally recognized care of the dying at end of life project.

Liverpool Care Pathway

The Liverpool Care Pathway (LCP) is a multidisciplinary and evidence based approach to caring for dying people in the last 48 hours. It defines desired outcomes over specific time frames, encourages documentation of variances and provides an excellent opportunity for evaluation of care. The LCP has been identified as a universally acceptable tool to facilitate pro-active end-of-life care. (Ellershaw & Wilkinson, 2003). A key feature of the LCP is that it empowers all health professionals, regardless of setting, to deliver optimal care to dying patients. The LCP encourages staff to be proactive in planning care and to

ensure that anticipatory medications are prescribed in the event the resident develops further symptoms. It encourages forward planning in an environment such as an aged care facility, where there is not an on-site doctor or stock medication available.

Mirando, Davies and Lipp (2005) identified increased confidence and knowledge of health-care professionals as a benefit of implementing a pathway. Health care assistants reported that the opportunity to attend palliative care education sessions made them feel valued for their role in caring for dying patients (Jones & Johnstone, 2004). The use of integrated care pathways represents a significant move towards outcome based practice in palliative medicine (Ellershaw, Foster, Murphy, Shea & Overill, 1997). This allows ongoing evaluation and improvement in clinical practice. Jones and Johnstone (2004) reported that the successful introduction of the LCP in aged care facilities required staff to extend their generic skills to encompass the principles of palliative care.

The opportunity to be involved in a new initiative within an ACF to pilot the introduction of an end of life plan of care occurred as a result of the relationship that had developed through the PCNSE role. Palliative care education to registered nurses and to the caregivers had identified the need for a plan of care at the end-of-life. It was anticipated that the palliative care needs of the patients could be addressed in a timely manner rather than as a “chaotic” scramble. The Liverpool Care Pathway (LCP) for the dying was discussed as a way to address some of the concerns previously mentioned.

As a continuation of “finding out” how involved the care givers are in the care of the elderly at the end-of-life, the next section reports on the methodology used for the two phases of the research project.

CHAPTER THREE - THE RESEARCH DESIGN

In this section I provide an overview of the project, the research questions and purpose. I will outline the theoretical framework that supports this exploratory descriptive study. The overall research design has been informed by two significant research ideas - the Liverpool Care Pathway project (Ellershaw & Ward, 2003) and Life Course research (Daaleman & Elder, 2007).

The main aim of this project is to understand the role and life experience of the caregiver in the delivery of end-of-life care to the elderly in an ACF. The project is presented as it evolved i.e. in two phases.

The first phase reports on a completed project which ascertained whether the introduction of the LCP for the terminally ill/dying phase, in an ACF within the New Zealand context would show how caregivers can influence the quality of care given to the dying, through life experience and education. This phase involved a retrospective audit of five deceased residents' notes chosen consecutively prior to the implementation of the LCP; this step was followed by a retrospective audit of the notes of five residents who died after the implementation of the LCP. A qualitative analysis of the results of these two audits was then undertaken by the researcher. A focus group was then convened out of the staff in the ACF lead by the researcher to reflect on what was occurring in the setting through education about care of the dying person and in particular to discuss the usefulness of the LCP as a tool and its ease of use in the aged care setting. A qualitative analysis of the discussion which was taped and transcribed highlighted themes recorded as phase one themes. The researcher identified that analysis of this data provided some insight into the diversity in the roles of the whole staff group but especially highlighted the significance of the role of the caregiver in the ongoing care of the dying resident. For the purpose of presenting a refined report of the first phase of the research project in the thesis, only the analysis of the focus group transcript will be discussed.

The focus group involved in phase one focused on the multidisciplinary team which included a doctor and registered nurses, but it was the caregivers involvement and provision of care at end-of-life reported in the focus group analysis that really interested me and became the basis for the decision to extend this project into phase two to explore specific elements of the findings such as turning points and the work/life of the caregivers.

Subsequently phase two has become the main focus of the analysis as reported in this thesis but it is important to recognize that it sits within a bigger project. Primarily I realized that having conducted phase one that wanted to explore life course transitions and turning points in the work life of caregivers who have received education on the implementation of the LCP and who have subsequently been involved in putting what they have learnt into practice. I had observed that caregivers had modified their work world and positively influenced the quality of care for elderly residents. Exactly how this had occurred was unknown and to my knowledge this represents a unique contribution to the research on caregivers work life. My research goal was to contribute to a greater understanding of the relationship between caregivers and residents. Therefore I framed the research question as follows:

What are the life course transitions and turning points in the work/life dynamic of caregivers in ACF, who have received education and had experience of implementing the Liverpool Care Pathway?

Theoretical Framework

My personal philosophy, as presented in the previous chapter is one of caring and presence with the people I care for in my professional world and I feel a sense of responsibility to use a methodology that portrayed the essence of the care and compassion as conveyed by the caregivers. Thus I chose the paradigm of interpretive research with a qualitative method because it framed

my interest in questions that involve human consciousness and subjectivity. It values humans and their experiences in the research process (Roberts & Taylor, 1998). Brown (1999) describes the objective of the research is to acquire a deeper understanding. Further, the goal of qualitative methods is to produce a detailed, insightful description of the issues and processes involved in a situation or experience. It is conducted within the real world of individuals' lives utilising methods that generate data in a more flexible and sensible manner within the individual's own social world (Maher, 1999). I believe that the qualitative method is consistent with the project purpose and is best suited to how I personally wanted to communicate with others all the information I had the opportunity to hear. I believed it also valued the rich experience of the four remarkable women who disclosed their experiences to me honestly and without hesitation. They contributed extensively to this study and provided me with rich material to work with. I felt a responsibility to honour that trust.

Qualitative research encourages people to delve into their experiences. Davidson and Tolich (1999) believe that it allows the researcher to investigate small areas in great depth. This also supported my decision to interview the small number of participants for this study. The authors go on to say "that qualitative research does not seek to generalize to the whole population but to provide a precise (or valid) description of what people said or did in a particular research location" (p.34).

Validity in qualitative research involves asking the participants to confirm that the interpretations are correct. Roberts and Taylor (1997) state that "the participants are acknowledged as sources of information and their expressions of personal awareness (subjectivity) are valued as being integral to the meaning that comes out of the research" (p.100). This fits in well with my own views that the life stories of the caregivers were unique to them as individuals and theirs alone to tell. Reliability is often not an issue in qualitative research "as it is based on the idea that knowledge is relative and that it is dependent on all the

features of the people, place, time and context of the setting” (Roberts & Taylor, p.100).

Narrative research

Narrative research is increasingly used in studies of educational practice and experience (Moen, 2006), the purpose of the narrative being an attempt to understand the human experiences. The narratives also contain within them knowledge that is different from what we might otherwise tap into. Stories are compelling and nurses have always shared stories.

Patricia Benner (1984) is a qualitative researcher who uses the concept of the lived experience. Benner’s work has greatly influenced nurses to write about their practice through the use of exemplars from nursing practice (Benner, 1984). Her work has drawn on observation and the interviewing of nurses in practice. She identified that the sharing of knowledge between practitioners can greatly enhance clinical practice and extends nursing knowledge. Benner also challenges us to reflect on stories and poems from our nursing practice. I identified strongly with this concept and this has been confirmed by others (Watson, 1985). Clinical story telling is a powerful tool in assisting the listener and the storyteller to develop shared knowledge and a greater understanding of the culture of nursing practice (Moss, 1993).

The narrative methodology appealed to me as a way to engage with the caregivers as it enabled me to explore issues such as personal identity, life course development and the cultural and historical worlds of the participants. This project places emphasis on the caregivers experience and viewpoint and by giving them the opportunity to tell their story validates their own life experiences.

Narrative research is thus the study of how human beings experience the world, whilst narrative inquiry is the process of gathering information for the purpose of

research through storytelling. This research has the potential to empower and value the role of the caregiver and enhance a sense of well-being in them by acknowledging the value of their own narratives.

Life Course

Life Course is a paradigm that views people in context over time. It provides an understanding of individuals by examining events and experiences over a life span (Daaleman & Elder, 2007). It looks at their life experience and how that influences and shapes the way they make choices.

The life course experience talks about the journey in a life cycle and the events that mark the changes people make. This study will be informed by life course research concepts and life story concepts in narrative inquiry. Daaleman and Elder (2007) state that “life course principles direct attention to individual choice and decision making, endorse an awareness of larger social and historical contexts and promote an understanding of the timing of events and role changes” (p.88). They also view human lives within a matrix of relationships with significant others. Life course principles guide inquiry by enabling a holistic understanding of lives over time and across changing social contexts. The narrative approach using life story, informed by life course research would enable me to investigate the life course experience.

The Method

The first section of this chapter focused on the method chosen to support this research study. Within this following section I will explain the processes which clarify how I used the methodology, the overall project and the two phases of the study.

Phase One

To ascertain whether the introduction of the LCP will impact on the quality of palliative care provided in an aged care facility in New Zealand.

Purpose

The purpose of phase one is to ascertain whether the introduction of the LCP will impact on the quality of palliative care provided in an aged care facility in New Zealand.

The LCP is becoming internationally accepted as a safe and reliable tool to guide the application and evaluation of care received by dying patients (Ellershaw, Foster, Murphy, Shea & Overill, 1997; Ellershaw & Wilkinson, 2003; Mirando, Davies & Lipp, 2005). The focus group meeting will inform the research group of the appropriateness of the tool and its ease of use.

Focus Groups

The focus group was used in phase one as an approach to evaluate the LCP tool and gather feedback from staff involved in the education and use of the tool. Focus group interviews are interviews with groups of about five to fifteen people whose opinions and experiences are requested simultaneously (Brink, 2006). Focus groups essentially involve an intensive group discussion 'focused' around particular issues. In this phase of the study it was important to provide a safe uninterrupted environment where participants could freely discuss their experiences in using the LCP and contribute honestly. A disadvantage of the focus group is that some participants may be uncomfortable to talk in groups. The researcher therefore is required to facilitate the sessions and be skilled in encouraging all participants to voice their opinions.

Waldegrave (1999) asserts that focus groups provide a powerful means for gaining an insight into the opinions, beliefs and values of a particular segment of the population. Their strength lies in the relative freedom that the group situation provides participants to discuss issues and reflect on problems.

In order to begin phase one an ethics application with justification was submitted and accepted. The following statement outlines phase one of the proposed project.

As the (PCNSE) I introduced the LCP into the facility and provided the knowledge and skills required to enable staff to apply the pathway tool. Mirando, et al (2005) identified the value of a dedicated project nurse in establishing the LCP as part of the Welsh Collaborative Care Pathways Project. Jones and Johnstone (2004) also identified the need for a supportive specialist palliative care service to sustain the initiative and ensure high quality care for patients.

Ethical Considerations

The Central Regional Ethics Committee approved the project (Appendix I). The caregivers were informed about the project initially by discussing the proposed research with them and by inviting expressions of interest to be involved. An information sheet was given to those who showed an interest and a time made to meet with them to discuss the research (Appendix II). Staff were assured that participation in the focus group, which involved a semi structured interview that would be audio taped and transcribed, would have no detrimental effect on their employment at the facility. They were also assured that they could withdraw at any time. This semi-structured interview was audio taped with permission and transcribed verbatim and the researchers commitment to confidentiality reinforced. A consent form (Appendix III) was signed once they agreed to participate.

The focus group, which included caregivers, registered nurses and medical officer, met with the Researcher to discuss the usefulness of the tool and its ease of use in their particular setting. The LCP is a multidisciplinary tool, therefore I believed that the meeting should be multiprofessional. The meeting was carefully facilitated to ensure that staff were not inhibited by their colleagues. An opportunity was given to meet with the researcher in private after the meeting, should that be necessary. The focus group meeting was audio taped and the participants encouraged to discuss their experience through a set of semi-structured interview questions that encouraged discussion.

Semi-structured interview questions for the focus group meeting included the following:

- Tell me how using the LCP was for you?
- Tell me what difference you think you made to the patient, their family and staff?
- Do you have any suggestions to improve the tool?

Recruitment of Participants

An information sheet (Appendix II) was distributed to staff to explain the research project. I discussed the project with key personnel at the Aged Care Facility prior to seeking their participation. I also discussed the implications of ongoing involvement if they consented to participate. Potential participants would be any staff members of the AFC who are involved with the care of dying patients, i.e. medical officer, nurses and care assistants. No payment or assistance will be offered at any time for being involved in the project.

Protection of Participants

A potential hazard is the small number of participants who may be able to be identified. Special measures will be taken to ensure the researcher reports the findings in such a way as to protect their identity in time, place and person. Although the focus of the study is to emphasise the gain in quality care for the patient and a learning opportunity for staff, there is a potential risk to any staff member who may feel threatened by change to their practice or who have experienced a “bad” death experience in the past. Access to a counselor will be made available to those participants who may be adversely affected by their participation.

To ensure that the participants feel safe in terms of confidentiality, the focus group meeting will be held at a mutually agreed place where they feel safe and comfortable.

The participants were informed at the beginning of the study and during the study that they had the right to withdraw at any time and also withdraw any information they did not want retained from the focus group interview.

The participants were assured that no harm or prejudice to employment would ensue by their participation and the subsequent results of the research.

Protection of Information

All information will be stored securely in a locked filing cabinet. The audiotapes, transcripts and other documentation will be disposed of after a five year period, to allow possible future analysis of data. The transcriber of the audiotapes will be required to sign a confidentiality agreement (Appendix IV).

Treaty of Waitangi

The Nursing Council of New Zealand (2005) governs the practice of nurses by setting and monitoring standards of competencies for registration and enrollment. Cultural safety, the Treaty of Waitangi and Maori health are aspects of nursing practice that are reflected in the Council's standards (2005). In this project my respect for the principles of the Treaty of Waitangi and being familiar with issues of partnership, protection, and participation for the tangata whenua was central to enlisting the involvement of the multicultural mix of staff. These principles are incorporated into the philosophy and values of the contributing hospice and inform my day to day practice. The study does not specifically involve Maori who are under-represented in the ACF (Minister of Health, 2001). However if Maori patients or staff participants were involved and had concerns, the Maori Whanau Liaison Officer, from the contributing hospice was available to be consulted. (Appendix V).

Feedback to Participants in Phase One

Staff of the facility were offered the opportunity to review the research data prior to the findings being presented and published. Participants were invited to verify the accuracy of any statements made during the focus group meeting. They were invited to review and edit any statements that may more accurately reflect their views. They were also able to delete any information that they did not wish to remain. Their comments and suggestions would be valued.

Phase One: Data Analysis and Findings

I studied the focus group transcript and developed a thematic analysis. Through the detailed process, qualitative data were organised and several themes emerged which included: Improved symptom management, teamwork, calm serene atmosphere, preparing for change, staff satisfaction, quality of care, collegial support and communication. Each theme will be presented individually,

with quotes indented and italicised. Although one of the central interests of this study was to explore the caregiver role, the data analysis of the focus group included registered nurses and doctor. Caregivers in this project were involved in completing the documentation. Therefore education given to caregivers on assessment of symptoms was extremely relevant in the success of the implementation of the LCP into the facility.

Summarising Thematic Analysis

Improved Symptom Management

The emphasis was on ensuring the anticipatory medications for the LCP were charted. The pharmacist involved with the facility came and spoke with staff about the use of anticipatory (PRN) medication and arranged availability of same these on site. A pre printed PRN drug sticker for the drug chart, was developed to be signed and dated by the doctor involved.

So it's nice to be able to have a set, a clinical set ,and say in this context that we're in now this is going to be helpful and it's there if you need it, and using a sticky across the chart.....it's tremendous because it's all written (doctor).

As medications were now charted (as required), the registered nurses were able to treat the symptom immediately, instead of waiting for an afterhours doctor to visit the facility. Often, the resident was admitted to hospital if an afterhour's doctor was unavailable. Education around the use of medications ensured the appropriate drug was used.

The medications are more readily available because the doctors have more information on what to prescribe and what for. And they're more widely used now than they were before we started using the Pathway (registered nurse).

The registered nurses felt more knowledgeable about the use of the medication and felt more confident in their assessment of symptoms.

(It's) easier to know what to give the medication for. If they have symptoms it's easier to find out because it's right there on the Pathway, to know what to give when they have pain or....or anything (registered nurse).

Having the medications charted and on site did have a positive effect on management of residents at the end of life. Prior to the LCP being implemented, staff felt a huge pressure and responsibility to not only the resident who was dying but also to the other residents. With only one registered nurse on duty in the afternoon and night, often many hours were spent trying to access afterhours care for medication, often with an admission to hospital the only option available.

The positive outcome was that having PRN medication charted saved the need for out of hours medical calls and more importantly prevented an admission to accident and emergency, which in itself was quite traumatic for everyone involved, including the resident, family and staff.

We had to try and get a doctor in to come and chart it or try and get hold of someone to get it charted, and then we may not have always had it on site. It just meant we had more to do, trying to rush around and get things charted. It just made the process a lot more difficult for the patient and the family (registered nurse).

There was overwhelming agreement that although the medications were not always required, having anticipatory medication made a huge difference. The relief of symptoms experienced in the last hours of life made the difference not only to the resident but also the family. Family may otherwise have been left with the memory of moist respirations, labored breathing or agitation.

Teamwork

An important theme was that the LCP enhanced the sense of team.

It also brings your staff closer together, because at the time we're caring for someone who is dying we are very close, very caring of one another, not in a rushed environment. You're just there for the person, and it allows you to be calm too around the person (registered nurse).

The multidisciplinary approach of the LCP was appreciated by the facility doctor who at times felt he alone had the responsibility to make the decision about end of life care.

One refreshing thing about the Pathway per se and also what families get, is it's remarkably not doctor driven, and I think that's important to note. That's not to abdicate responsibility, but that's remarkably important - that it's driven by people who are day-to-day providing care (doctor).

Calm Serene Atmosphere

It was observed that since the introduction of the LCP that there was calmness around residents who were dying. There was less "drama" and a sense of acceptance by relatives that their loved ones were well cared for in a peaceful environment

I've found that the relatives, when they come in, they feel it's a calm, serene atmosphere for them and they don't feel that they are in a room where someone is [passing over] and they've got that fear about them (caregiver).

The multicultural mix of staff added to the appreciation of giving individualized care. Some caregivers were timid and hesitant at expressing themselves but with encouragement provided valuable insights into the sensitive and caring way they provided care to the residents.

I find that the individual care through the Pathway is really good because when you enter the room the patient is doing the individual care, they have started to prepare the room and it's really peaceful and we look at the person, it looks so comfortable and the room is like filled with flowers and candles, It's a different feeling when you enter that room, it's really peaceful (caregiver.)

Preparing for Change

Staff were more proactive in discussing when a resident's condition was deteriorating with relatives. Conversations with the resident (if capable) and family, prevented inappropriate admissions to hospital at the end of life.

Communication with family and whanau is a key feature of palliative care principles, and the conversation around end-of-life care is essential when including the patient and family in the plan of care. Explanation of information given is vitally important. People often do not understand the written word but the conversation around what it means is essential.

From the relatives point of view they feel comforted knowing that, they feel supported, they feel that's the best option to be nursed here – and in that respect, the tool has got several uses (registered nurse).

The conversations with resident and family prior to starting the LCP proved to be a way of preparing the family and involving them in the plan of care and place of death. The staff were more proactive in planning care at the end of life.

One lovely thing about the pathway is that many decisions are made in advance and they are made in a collective way that's much more driven from the grass roots (doctor).

The nursing staff felt more relaxed about having the conversations around death and communication

All the relatives were shown the tool and given a copy to look through before the pathway commenced, and they found that very good for them – as well as the talk – that proved to be very good. We've talked about the pathway before the actual event, so people are familiar (registered nurse).

The caregivers were actively encouraged to be involved with all the cares and documentation on the Pathway with overview from the registered staff. Prior to the LCP, caregivers were afraid to answer simple questions from relatives and referred everything back to the registered nurse. Although they knew their scope of practice, it was encouraged through education that they were able to sit with relatives and answer the questions around the dying process.

Not only are we prepared for the resident..... and even the relatives – because sometimes the relative get upset that their mum or their dad or their aunties are really dying, and because of the tool it's more easy for us to explain and to prepare them for the dying process. So it's really good (caregiver).

Caregivers reported that previously they had difficulty making families understand and accept that their relative was dying. Families were now more accepting than before the implementation of the LCP.

But since we have this system now it's much easier for us to make them understand and explain to them what they're doing..... Their loved ones and so I found that now relatives are starting to accept things. More accepting than before. Particularly for the

care workers, because first they come and ask us even before they go to the RN so.... So it's a big relief (caregiver).

The open discussions that now occurred with staff and families created an extended team. Relatives were more involved in the care as they were empowered by information and explanation of what to expect.

Staff Satisfaction

Staff, especially caregivers, felt more confident and reported an increased awareness of the palliative care needs of the residents at end-of-life.

Everyone's a lot happier – but in the last, you know, six months using the Pathway I've felt satisfied when I've left work that I've done my best (registered nurse).

The biggest impact on discussing the plan of care with the family was that they now became more involved if they wished.

The family input....I did notice the pathway included a lot of family who took over a lot of the care as well...and...other family turning up to massage them and taking over the care (caregiver).

There was provision in the facility to access extra staff for the dying resident through end of life funding. This funding provides care to people who are dying through the provision of twenty four hours individualised care at the end of life. This extra funding was a result of a submission from the PCNSE to the local District Health Board to assist in the delivery of quality palliative care to the dying resident through individualised care at the end of life when required. The extra care meant that a caregiver or registered nurse could be assigned on a one to one basis, depending on resident need. A list of caregivers' names, to be called at any time day or night, was compiled. This was a list of those staff

interested in palliative care that were available to do extra shifts to provide extra care to those residents who required it.

You're given over and above hours specifically to be with that person, you're not doing other roles and you're not rushed and I think that flows on to the person that you're there with them (caregiver).

This extra care was used as necessary and especially if no relatives present to sit with their dying relative. The “value of presence” was recognized as an important part of the care given to meet the spiritual and emotional needs of the dying person.

You're there for the sole reason of being with the dying person, putting music on if they want it, massaging if they want it, hold their hands if they want it. And it makes a difference because they're calm. So the extra time is really valuable (caregiver).

Quality of Care

The LCP was identified as having impacted on the quality of care of dying residents, especially that they were not moved from one area to another when they entered the dying phase. Residents in the dementia unit now remained where they were and were not automatically shifted to hospital level care.

I find it absolutely wonderful that people can stay in their own rooms and in their beds in the area they have been living and that is where they will finish their life, in a room – OK, it's just a room, but it's been their home for maybe for two, three or four years – so gone is the practice of taking them out of that room and putting them in a new room just to die (registered nurse).

This was seen as an enormous change in the facility and a huge quality improvement for the home.

We have taken a lot of fear and mystique out of dying. It has removed the hospital aspect of dying, whereby it's going to be a clinical event, and we have made it a more humane event (registered nurse).

The LCP documentation provides clear information that was easier to follow particularly at handover from one caregiver to another. More detail was transferred at the end of a shift with the caregivers feeling more empowered and involved.

I've come and taken over and that documentation you look at it and you can follow it and you can see what she's done, and you can follow on with what she has been doing. And I find that very good. And when the next person comes on you can explain what you've done and show them, and they know just to continue on with that as well (caregiver).

Collegial Support

Evidence exists of the stressful nature of working with the dying patient and their family (Vachon, 1997; 2001) therefore any means of minimising this stress will benefit the caregivers involved. In an environment where professionally qualified nurses are at a premium, a clearly documented Pathway may remove some of the stress for caregivers who provide the majority of care in aged care facilities.

The meetings that we've had, our fortnightly meetings, I've noticed that they have been a good forum for the caregivers to debrief. I do believe that it's very important that we look after our caregivers'

emotional needs, because you become emotionally involved with that person and with the families that there is a grieving process to go through. So the meetings have been used in a way, as a debriefing process (registered nurse).

The Unit Manager acknowledged that the main care provided to residents was by unqualified staff and was very supportive and encouraging of the valuable care they provided. She recognised the increasing workloads and the stress that was generated by not having enough time to do all that was required or more importantly what they wanted to provide. The increasing dependencies of the chronically medically ill meant there was less time to debrief the staff on the increasing number of deaths they encountered.

...and it's a very hard physical job and not well paid – we all know the issues – I'm finding more of my staff are getting more issues around stress and, you know, not getting adequate debriefing, professional supervision... but it really is hard to be all things to all people and you aren't skilled often in dealing with the level of problems that are there – and a death can bring up a lot of things, and you don't ever get a chance to move on (registered nurse).

The continuing liaison and regular presence from the PCNSE strengthened the relationship with the facility. An equal partnership resulted in the facility staff feeling well supported in their work.

Education

Due to a lack of resources, time, staffing shortages and turnover, a few key staff members were relied on to drive the project. Informal education sessions with interested caregivers and trained staff were the catalyst for change. Patience and understanding of the researcher was rewarded by increased interest and commitment from the staff. One particular staff member championed the project

and had a huge role to play in facilitating meetings and updating interested staff in the progress of the implementation of the LCP.

“I’ve actually seen the staff develop in that area (care of the dying) since they have had this process to follow – they’re very comfortable and knowledgeable now and feel at ease with the whole process. None of you are afraid to talk about a person dying, you actually are using your experiences, and what I see is you’re actually talking about things that are coming from a personal perspective (registered nurse).”

Conclusion

The focus group findings validated that the implementation of the LCP into an ACF facility improved the quality of dying for residents, but it is difficult to measure the ongoing impact of the LCP without further research. The increased awareness of palliative care needs at end of life was supported by education and the doctor and registered nurses were able to discuss freely the transition from curative to palliative care. The caregivers felt part of a team and felt their contribution was more valued than prior to the introduction of the LCP. This focus group, as mentioned previously, included the doctor and registered nurses. The forum provided a relaxed atmosphere where all participants felt free to participate. My impression was that the caregivers welcomed the chance to tell their story and how they delivered care and were not restricted by the presence of the other health professionals. Their enthusiasm and passion for improved care for dying residents and insights gained from this observation steered the course for the next step of the project.

Stepping Stones: Phase One to Phase Two

The results of the focus group revealed powerful insights into the work of the caregivers. Their contribution to end-of-life care deserved further exploration. In the next section I want to discuss not only how the implementation of the LCP in this particular ACF affected the care of residents, but also how it impinged on the personal/professional development of the caregivers. I wanted to explore avenues for enhancement of that care and explore possible ways to further this development. I therefore framed this interest as a distinctive new step in the research project and discussed my intention to interview some of the caregivers in-depth about their experience of caring for the dying elderly person especially after the training programme with the manager in the ACF.

Phase Two

I framed Phase two of the project around the following research question: How does a caregiver's life experience influence the care they give to the elderly at the end of life and how does education influence their wellbeing?

Purpose

The purpose of this phase of the research was to specifically explore caregivers experience in caring for people who are dying, to identify what they consider they bring to the role and what influence education has had on their work life.

Ethical Approval - Phase Two

When commencing the second phase of the research, a letter was presented to the Central Regional Ethics Committee (Appendix VI) seeking approval to extend phase one of the research to explore the experiences of care assistants who work in aged care facilities further. This stage was given approval. (Appendix VII).

Participants

Participants were recruited verbally by invitation of the researcher. The reason for this style of invitation was that I was interested in the caregivers who I considered had most readily demonstrated a caring component to their work and had expressed an interest in education and a thirst for ongoing education. I had had the opportunity to observe the change in care practices over the previous five years and had identified that the quality of care delivered to residents depended on the skill of the caregiver. I knew that my longer term vision was to identify characteristics or attributes health care providers or employers needed to be aware of when employing new staff. But I was also interested in what I could learn from an unregulated workforce who emulated the role of the nurse without the training that is required of a registered nurse. I considered that they were in a challenging situation in the work setting and they had shown a real capacity to change practice after specific training.

The initial conversation occurred with each caregiver that I had identified separately inviting their involvement; conversation was framed around the research project, my interest in their work and the kind of question that I would frame to elicit their own life story journey, the challenges and turning points. Once this initial conversation offering an invitation had occurred with the caregiver an information sheet (Appendix VIII) was given to the person who at this point was still a prospective participant. The information sheet explaining the project was read to the person and the text identified where they could agree or not agree to participate. The consent form was read as well and the potential participant was given the opportunity to have some time to consider the request. They understood at the outset that they could withdraw at any time. This carefully conducted conversation was instrumental in engaging the trust and interest of these participants. A periods of one to two weeks elapsed between the initial invitation to participate and the researcher being in touch with the caregivers by telephone to inquire as to their wiliness to be in phase two of the project. At this phone call a time to meet was arranged and the

consent form was then signed by both participant and the researcher. (Appendix VIII).

Relationship between researcher and phase two participant caregivers

All participants were known to the researcher through on-site education (within the ACF), had attended the Palliative Care for Care Assistants Course and had been educated in the use of the Liverpool Care Pathway. They had also been part of the focus group in phase one and understood that patients notes had been audited. The caregivers who had indicated their willingness to be interviewed had demonstrated to the PCNSE as researcher that they were particularly keen to explore end of life dying and to share their experience of having changed their own practice as a result of the education.

Interview Process

I had constructed a semi-structured interview plan, with open questions to guide the initial interview considering that this format was more likely to encourage the participant to tell their story. An inductive technique was employed, so that participants' views and concerns, rather than those of the researcher, were allowed to guide the interview. This method is supported by Roberts and Taylor (1998) who confirm that;

“Qualitative interviews are more like conversations than interrogations and can be structured with a list of set questions to be asked, or they can be relatively unstructured with little more than an invitation being issued by the researcher for the participant to talk about an area of interest” (p.178).

I attempted to make the interviews as much of a conversation between myself as the researcher and the caregiver; this meant that the participant was less conscious of the tape recorder. Since I had had the opportunity to have what I considered were natural conversations in the work setting prior to the introduction of specific education on care of the dying person, when these participants had asked me many questions and shared their insights, I affirmed that this style of conversing would underpin the interview conversation that I wanted to tape. I felt it was most important to get as much of this natural way of being that I had observed before instead of orchestrated answers. It transpired that the set of questions prepared to guide the interviews were not strictly adhered to, as the caregiver often unsuspectingly answered the questions in the telling of their story. Roberts and Taylor (1998) also discuss that;

“Data for qualitative research can be gathered easily and effectively through having people relate stories that are relevant to the research. Participants may feel that they have little to offer to a research project but they do respond to an invitation to tell a story” (p.182).

Phase Two: Data Collection

All interviews were taped and transcribed verbatim. The researcher listened to the tapes following interviews to decipher if there was any background data that was important or gaps in the transcript. The transcripts were then carefully managed and systematically evaluated.

Data Analysis

In attempting to analyse the rich data from the interviews, I initially struggled to capture the essence of the story in themes while maintaining the integrity of the participants' stories. Agar (as cited in Oliver, Serovich & Mason, 2006) argues that transcription is a pivotal aspect of qualitative inquiry. Oliver et al (2006) also suggest that transcription is a powerful act of representation. With these

thoughts in mind I was very aware that the validity and reliability of my interpretation of the transcriptions of their life story narrative was crucial; and I had no wish to do the caregivers an injustice by inadequately describing what they had shared with me. My original intent for this thesis was to find out how the caregivers life experience can influence the care they give to the elderly at the end-of-life. I was mindful that trustworthiness and authenticity in the research is maintained when the analysis holds close to the participants' stories. In searching the literature and with help from my supervisor I was alerted to an article by Joakim Öhlen (2003) who presented a model for poetic condensation of oral narratives to enhance the evocation of the meaning of suffering.

Poetic Condensation

In this article Van Manen (1997) stated, "text that creates evocation of meaning brings to immediate presence, images and sensibilities that are so crisp and real that they in turn evoke reflective responses such as wondering, questioning, or understanding" (p. 354). When I saw how Öhlen (2003) had interpreted the narrative, I immediately wondered if this would work for the transcripts I was now trying to analyse.

There is very little written about this method of analysis. Öhlen (2003) reported on this method in a research article investigating the meaning of suffering. His aim was to present a model for poetic condensation of oral narrative to enhance the evocation of the meaning of suffering. The verbatim transcripts of audio taped interviews are presented like a poetic transcription. This is achieved by starting with the verbatim transcripts then eliminating all the interviewer's words and everyday talk of the participants to create the poetic transcription. Gee, as cited in Öhlen (2003) developed this model which "is based on the assumption that an oral narrative can be organized into sequence of lines, which can be shaped into stanzas" (p.559). The stanzas consist of four lines that now and

then are interrupted by single-line expressions. Öhlen (2003) reorganized the stanzas into four or more lines to keep meaning within each stanza.

This method appealed to me as I immediately saw that poetic condensation illuminated life as it had been lived. Rather than capturing it I could see I would be releasing the text. Interpretation of data involves interpreting the participants own words so the reader can get a true sense of the person and their life; the researcher creates a vehicle to release the essence of their story. I experimented with the condensation and modified Gee's (1991) interpretation method to present the caregivers stories. This method allowed me to enter their world and release valuable untapped knowledge as I listened to the stories. I was surprised and delighted with the clarity of the resulting story as told by the caregivers using their own words.

Life course Interviews

The interviews were constructed with the following prompts

- Who are you –your life experience?
- What has caring meant for you in your life?
- What do you bring to the workplace?
- How was the experience for you when we first met?
- What did it make you think about?
- What difference has education made to you?
- How did that make a difference to you in caring for your own self and in the work setting?
- How has that affected your work and well being?

- An example - how did education help you?

Conclusion

The interviews with these four remarkable women were both sensitive and powerful. The caregivers interviewed shared very personal parts of their lives which gave an insight into why they chose this type of work and how their own life experience added value to the care they gave to the elderly. Their work lives linked in some way to their earlier life and experiences encountered during their life course.

In the next chapter I will introduce the four remarkable caregivers who disclosed their experiences to me honestly and without hesitation. They contributed extensively to this study and provided me with rich material to work with.

CHAPTER FOUR – LIFE STORIES

This chapter will present a section on each of the four caregivers I interviewed. The first text describes the caregiver and identifies their background story and the second text repeats this description but in a different format I have termed the poetic condensation. I created this second text to capture the essence of the person. Both of these texts were developed from the transcribed interviews. These two texts are then followed by a third text that identifies the response made by each caregiver to the question about what they understand was a turning point for them in their life or work life. The fourth text is written for each person and identifies a 'caring moment' which I captured from the interview conversation. I conclude each life story with my reflection on their story.

“A caring moment occurs whenever the nurse and another come together with their unique life histories and phenomenal fields in a human-to-human transaction. The coming together in a given moment becomes a focal point in space and time. It becomes transcendent whereby experience and perception take place, but the actual caring occasion has a greater field of its own in a given moment” (Watson, 1985).

During the interviews each of the caregivers had the opportunity to be listened to feel valued. The context within which I engaged with the caregivers is reflected by Bingley, Brown, Reeve and Payne, (2008) who state that “the telling of stories is an integral part of human social communication – occurring in all types of textual, verbal, nonverbal and creative expressions” (p.653). Furthermore “both the patient and health professionals’ stories have much to teach us about living with life threatening illnesses, suffering and the experiences of care (p.654).

Margaret

1. Life Story

Margaret has been a caregiver for 17 years. Born on a Pacific Island, Margaret saw caring and looking after one another as part of daily life. Her role models were her mother and grandmother and in their home village day to day life centered on looking after one another which included their extended community.

Margaret and her family came to live in New Zealand whilst Margaret was still at school and Margaret observed the same caring and role modeling with extended family in New Zealand, particularly in the life style of an Aunty. In time Margaret's mother who was a nurse moved back to the Islands and Margaret stayed with her Grandmother. She revealed how her Grandmother taught her wonderful values and there was an expectation that work was important and she made Margaret promise she would work. Margaret forced herself to work in computing but was never happy. Her Grandmother got sick and Margaret then worked part time so she could look after her Grandmother.

After a move to another city Margaret felt unfulfilled in her office job so answered an advert for work as a caregiver.

I booked an interview and I went up and they asked me what I've got, you know experience and I said no I don't have any experience but I've been watching my family

Margaret successfully gained employment and has been a caregiver ever since.

I have never ever felt so happy in all my life

Margaret's grandmother was a huge influence on her life. When Margaret went back to care for her when she was dying, her Grandmother left Margaret with

something that she has always remembered, especially when caring for the elderly.

The last thing she ever said to me, and these are her exact words, she said to me you have to remember respect and dignity that's the first two things you have to look at before you do anything

Margaret wants to be a registered nurse and on two occasions she has started but each time a family member has got sick and she has left to care for them. Caring for families is an instinctive act for her and family always comes first.

At the time of the interview Margaret is married with a loving husband and four children. She is an experienced caregiver. In recent years several experiences in her work have threatened to impact on her role as a caregiver. These experiences resulted in Margaret reviewing her work and questioning if she was able to continue in the job that she loved passionately. Two very special residents died and this was a turning point for Margaret who had to make choices at a time she felt low in spirits.

When she passed away it left me with a huge, a huge, I mean talking about huge impact on my life. I was sort of very unhappy, unhappy and it was like a hole in my heart that she left for me

Margaret recognized the stress that she was experiencing and sought professional help which resulted in her reviewing her work and home life. She developed remarkable coping skills which included debriefing sessions with her husband and as a consequence this activity changed the way she viewed herself and the work she did.

Another experience that inspired Margaret was the palliative care education sessions that she attended. These courses encouraged Margaret and gave her confidence as she realized she had the knowledge but the education made her think more deeply about how she practiced and how self care was as important if she wanted to continue work as a caregiver.

2. Poetic Condensation

*My growing up was
caring for people
That was something that I've seen
with my own grandparents.
In my growing up I used to see
the passion and love
that they used to give.*

I'm from Samoa.

*My great grandparents
To my grandparents
To my parents,
They got involved a lot with
the people in the village.
I've actually seen all of this.*

*It was more or less
one of the things
that's been passed on.
It was a natural thing,
It came from my heart,
Came from what I've seen*

With my own family.

*My grandmother
She was very proud*

The last thing that she ever said to me....

She said to me

You've got to remember

Respect and dignity

That's the first two things

You have to look at

Before you do anything.

Every now and then

I stop and think

Respect and dignity

I wasn't well educated,

But you know,

It's how you do the job.

It's who you are.

What you learn

From your past.

As a caregiver as long

As you've got the passion...

And the love for who

you're going to provide for

They will be happy of...

What you can give

In this opening poetic condensation of the verbatim transcript from Margaret's interview, I immediately felt connected to someone who had a genuine compassion for the people she cared for. Margaret was very comfortable with

who she was and brought a lot of life experience to her role as a caregiver. Her background and past had installed strong values of humanistic caring and this was enconced in her everyday actions at work.

Education did help me a lot.

The first time I met you

There was a lot

Of encouragement

It was a lot of things

That I've learned

For the first time ever

It built up more confidence in myself

And it's the knowledge

That I've learnt

Boosts up my being

A caregiver.

Sort of gives me

More confidence

To deal with families as well

I used to think I was going

To say something wrong.

I didn't have the proper words.

Now I've got more confidence

In myself

To talk to the family.

Everything I've learned,

*All the training,
I pass that through
To others at work
A special sort of session
And then
When we start the palliatives
The care assistants come to me
And say how do you do that?*

Why do you call it palliative?

*I said to them
Palliative is not
What you think it is.
Palliative care is not
Just for people*

Who are dying

*It is actually for every single individual
In this home
And what I can do for you,
To help you out
If you want to understand more*

Come and see me

*I can buddy up with you
I'll be able to pass you
That knowledge
Because I might be good*

*At telling you
But you might not be good*

At doing

*If you actually want
To see me
In action
I'll show you what
It's all about
I am always passing
On the knowledge*

Every single day.

The palliative care education sessions that Margaret attended were a turning point in her life. She realised that the work she did was of value and she had been able to contribute her views within a professional setting and she had been listened to. Margaret often referred to the “deeper knowledge” she had gained from the education sessions. She now felt more confident when caring for residents who were dying. Lillyman and Whittle (2000) as cited in Ghaye and Lillyman, (2000) discuss how students had realized what they had learnt within the course as a whole and how they had been able through reflection, to verbalise this and demonstrate a higher level of thinking in relation to their practice (p.54).

The ‘knowing how’ and ‘knowing why’ was evident within the caregivers’ discussions as they related stories to me. Telling stories, the narrative, was a way the caregivers made sense of their practice

Last year I had lost two

*Very special residents
And one this year
I get attached to people*

*One particular resident
Wrongfully diagnosed by the doctors
During her days
Ended up somewhere else,
In a mental institute,
When she came in here*

*Never let anybody shower her,
Never let anybody dress
Never let anyone give her a cup of tea,
Never let anybody give her food.
I was her only home
I just lost her about a year now*

Looking after her was an honour.

*I was happy going home,
Once I'm outside the gate
I shut my work altogether
And then I go home.
I think of them all the time
I was happy you know*

I was happy

*When she passed away it left me
With a huge,*

*I mean talking about huge
A huge impact in my life.
I was very unhappy,*

Very unhappy

*And it was like a
Big hole in my heart
That she left for me.
When she left me,
I thought my life
As a caregiver was over.*

*My husband and kids
Tried to take me out
To sports and watch
But I had an empty space
In my heart
Cause you know....*

She was part of my family.

In this scenario Margaret shared her deep sadness when special residents she cared for many years died. Caregivers in ACF form special relationships with residents that may not be as evident for nurses in acute areas. The caregiver tends to do all daily tasks with the residents and enters their world. Another resident who Margaret was especially close to died and Margaret wondered if she could continue with caregiving. Without direction, she sought help from the local funeral directors who offered counseling to families. Margaret had recognised in herself the need for help. It appeared she was suffering from cumulative grief.

*Another resident
Oh no here we go again
I've got a very
Understanding husband
I was so very unhappy
Again*

*I had a dream
A dream or a vision
It was very clear
She was standing
On the mountain
Looked down at me
"Margie"
Wipe those tears
Everything you gave me*

Give it back

This powerful description from Margaret of her grieving made me understand the depth of feeling and connection she had with the residents in her care.

Parkes (1998), a Palliative care physician whose research has guided the development of the Hospice philosophy in New Zealand advocated that in order to help those who are dying, we must be prepared to get close to them, to share their fears and to stay with them in their fears. This involves a deep level of communication which offers the double-edged sword of care being both an absolute privilege and a sometimes painful experience.

*When Bob passed
I had the same dream.
This time
I was on top of the mountain
He was talking to me
On the same level
Then Mavis passed away.
I had the same dream*

They got me a doctor

*He said
Sometimes you know
On top of the mountain
That is telling you
That you are going to go
Above the level
That dream is actually telling me
It's time for me to move on
Pass it on to someone else*

That's exactly what I'm doing.

*I have a
Very supportive husband
Cause I talk about it as well,
The thing is, that it really works
My husband and I debrief each other
We always set a time
When the kids know
That Mum and Dad*

*Are actually sitting quietly
Having a chat
That means we are debriefing ourselves*

And that works

Margaret's description of her debriefing sessions with her husband was a turning point in her life. Without this conscious effort to manage the stress that she had experienced she recognised that she would not have continued with care giving. Mitchell as cited in Maher (1999) claims that:

the main aims of debriefing is to assist or accelerate recovery in normal individuals who are experiencing a normal reaction to an abnormal event before harmful stress reactions have the potential to damage their work performance, their careers, health, social and family life (p.76)

Margaret clearly identified that once she talked about her feelings openly, she was able to continue in the job she loved. She went on to explain how education had influenced her choices of her life course at that time.

*After I did all my training
At the Hospice
And then use it,
Pass it on
That was a huge change*

*It gave me the great pleasure
When I did all my training
At the Hospice
Without that training
It would have ruined my career
Altogether as a caregiver*

*Cause I stop and think
And it didn't happen before*

*You know
Stop and think
Of who you are
What you're supposed to do,
Your responsibility
About your work,
It does help you*

It does.

3. Turning Point

Several things have happened in the last year or so that have changed the direction of my life. In the last year, three very special residents died. I had become very close to them, especially one, and was very happy caring for them. When they passed away it had a huge impact on my life. People I had looked after had died before but it didn't reach the point where I didn't want to be a caregiver anymore.

And then the other day I was dreaming of them. Mary (pseudonym) was standing on top of the mountain and, I don't know whether it was a dream or a vision, but it was very clear. She looked down at me while I was standing down the bottom of the mountain and you know, these are her exact words in my dream, she looked down at me and she says "Margie, you wipe those tears off. I want you to wipe those tears off, the knowledge, everything that you've given to me I want you to give it back to someone else".

I had several other dreams but each time I was higher up the mountain. I had to seek help from a counselor and a doctor and they said to me that sometimes, on top of the mountain is telling you that you are going to go above the level. Having that dream was actually telling me that it's time for me to move on, pass it on to someone else and that's exactly what I'm doing.

The help I received helped me make the decision to stay in the job I loved.

This had not happened before but after I came to the palliative care education sessions at the hospice, I learnt such a lot and realised that to care for others I firstly had to care for myself. The knowledge I gained inspired confidence in me and gave me a deeper level of understanding of how valuable my role is. Without that training it would have ruined my career altogether as a caregiver because now I stop and think. The education has helped me make a change in my life.

I have now made a decision to go nursing next year and have already enrolled.

4. Caring Moment

“A lady I was caring for, she was dying. I had known and looked after her for seven years. There was this huge bond with her and with the family as well. I was feeling so sad and the last words she said before she closed her eyes and took her last breath, and Bob her husband was there, was something I will never forget. She said to me “Margie, I love you, don't give up”. And even though that I was quite emotional after that I realised that she tried to tell me, you know, don't cry for me just carry on. And ever since that time it was different from the others times that I didn't want to be here anymore. Her husband, he just looked at me and he goes ‘there you are I don't have to tell you a million times’. Because he, you know, him and I, I look after Mavis for seven years and that is why you know him and I we've got this huge bond and the family as well. We've got a huge bond and it doesn't matter what I do or what I say they're

always going to be part of me and that's what really makes my job so easier. That gives me the strength and gives me you know it makes me think twice about my job and about my family and I have never ever been so happy".

5. Reflection

In the narrative above, this caring moment came from the resident to the caregiver. Margaret had developed close relationships over a period of time with particular residents and their families. When relating this moment with me as researcher she told me that she had been very unhappy since the death of two other residents that year and was questioning if she would be able to continue in the role as a caregiver. This moment between resident, family and caregiver illustrated the depth of care that often goes beyond the 'looking after'. It is difficult to measure this kind of care. The human act of caring from one person to another. Noddings (as cited in Sanford, 2000) stated "Caring involves two parties: the one caring and the one cared for". It is complete when it is fulfilled in both" (p.9).

I concur and endorse this insight from Vachon (2001) who comments "this is one way in which professionals (caregivers) often maintain continuing bonds with people who have died. They carry the lessons learned from those who have died forward into the care of those who they have yet to meet". This use of text to reveal the essence of the caring moment conveys my own views of how Margaret continuously delivered compassionate care to all the residents.

In a study by Goodridge, Bond, Cameron and McKean (2005) the caring behaviors of the staff were identified as critical elements in the dying process (p.231). Staff often had long-term relationships with residents and Margaret's story highlighted how strong that tie could be. Emotional support of both the resident and family was recognized as key to quality end-of-life care.

Jane

1. Life Story

Jane has been a caregiver for six years. Jane experienced a difficult childhood, married young and continued to experience tough times throughout her life. She was taught right from wrong but cannot remember being shown how to love or given any “heartfelt” care. She had low expectations of life and has always felt that her love has been in other people’s hands. She constantly felt put down and had no confidence.

Later in her life story, she revealed how in her previous occupation, she was involved in a traumatic and life threatening experience at work. This episode was a turning point for Jane’s and changed the way she viewed life.

People say all the time that life’s so short but until you have a tragic thing happen personally it doesn’t trigger and you don’t appreciate that little things mean a lot to other people

The care and support she was given by health professionals was the first time she had experienced a sense of caring and she was able to “let a lot of stuff go cause I had the right channels”. Jane had a change of direction and went into the role of caring for people as she wanted to give something back to people.

I know how I like to be treated and if you can treat other people how you like to be treated.....you can learn all the studies but if you can’t give a bit of caring.... if you can show a bit of care you get a better response

Jane’s traumatic life experiences developed in her a sense of hopelessness. The professional help she received from a caring health professional at the time of her traumatic experience was a turning point for Jane. Subsequently, her life experiences made her stronger and she was now able to make choices. She now has a loving husband who is proud of the work that she does.

The way I am cared for by my husband I have never had in my life. It's what you expect from parents. To be given it in the last 5 years just makes you appreciate and there are some people (a lady) in the rest home that have had similar experiences but they still remember the bad times too. I just comfort her saying you are safe and loved and she 'quietens' down

Jane now appreciates life and feels appreciated by the people she cares for. Her home life gives her well being which she transfers into her worklife. She understands that the people she cares for are dependant on her role as a caregiver to give them a bit of joy ... *"I think I bring a little joy because I have a little happy bubble that I can share"*.

2. Poetic Condensation

*I almost lost my life.
I just wanted to give
back to people
Who couldn't help themselves.
I went into the role of caring
For people to
give back some life.*

It changed my total direction.

*Until you have a tragic thing
happen personally
It doesn't trigger
You don't appreciate
that little things
mean a lot to other people.*

*Growing up,
I was not shown any love.
Mum was the same
So I left home.
I was taught right from wrong,
I wasn't given any
heartfelt care*

*But I've had quite a few
traumatic experiences
through my life
Each time
I grow stronger
Then I decided
to give back to people
Who couldn't*

Help themselves

*They are people
who need other people
To help them
Just make them feel
like people again.
I can give them*

That love and care.

*The way I'm being cared for
Now by my husband,
I have never had that*

*in my life.
It's what you expect
from parents.
To be given it
In the last five years
It just makes you*

Appreciate life.

*There are some people
in the rest home
That have had similar
experiences
But they still remember
the bad times*

*There is a lady...
I don't think
She has had much love
in the marriage
I just comfort her
Saying you're safe, you're loved
She quietens down
And smiles.*

Just little things.

Jane could identify with this lady and used her understanding and compassion to create a caring moment. According to Jean Watson (1984), a noted nursing theorist, a caring occasion occurs whenever the nurse (caregiver) and another come together with their unique life histories and phenomenal fields in a human-to-human transaction. *'We learn to recognize from one another how to be*

human by identifying ourselves with others, finding their dilemmas in ourselves. What we all learn from it is self-knowledge. We learn to recognize ourselves in others' (p55). Jane had that self-knowledge and as a result of making a life choice was now able to help others. Her compassionate and caring self was profoundly moving to observe.

*There's duties
And there's going that
little bit further
From the heart
But you can see
them smiling,
You can feel them smiling.
It gives you a purpose*

To be here.

*When I come to work
I think I bring a little joy
Because....
I have a little happy bubble*

That I can share.

Jane attended the palliative care sessions and was part of the special interest group. She was one of the caregivers who volunteered to sit with people who were dying and also helped with the recreation. She spent a lot of time getting to know the residents and their special needs. When I first met Jane, as an educator she reflected on why this education made an impression on the way she now viewed each resident and how this impacted on her practice

*You're a very
caring person
It was a very positive
experience
Because you opened our eyes
that these people*

Can die with dignity,

And that what we are doing

It's OK.

*Giving them,
that care and affection*

heals,

Not life healing

But wound mending

From the past.

You introduced palliative care

*That it is alright to spend
extra time with one person*

over and above your duties

Hold their hand

if they want you to

Just be there

You emphasised that

And encouraged us.

Treat them how

you like to be treated.

You just gave us

So much.

When asked what difference, if any, has education made Jane shared one experience of learning that impacted greatly on her and was something she then passed on to other caregivers.

A lot of difference

One session in particular

One example you brought,

You showed us

Photographs.

One was a man

He'd had a stroke

He was in his wheelchair

You had a caption

"I'm not a stroke victim

I am Mr ... I am an airline pilot,

I am a person in here"

I use it quite often,

Those photographs

just had an impact on me

Look beyond

their disease.

The one palliative care education session where photos of elderly people with captions underneath conveying 'who they really are' were used to remind caregivers of the 'person' they were tending to, had appealed to Jane's visual learning style. She found them very moving and from that time, completely changed her practice. An example was a photo of an elderly gentleman in a wheelchair, bent over and not able to sit up straight. The caption underneath conveyed to the caregiver his personhood.

*I was a farmer, nurse. Straight as the maize grew in the field, I tossed
bales of hay just as you toss me*

The story telling and visual prompts created powerful teaching moments. Education had a huge impact on Jane, especially the photos of elderly people with similar captions underneath.

*There were other people
Sharing their experiences
I learnt a lot,*

*I always wore bright clothes
Which seemed
to make a difference
I brought flowers from home
And if they wanted me
To hold their hand,
But just listen,
They had a lot to talk
If they were able.
Just being there,
Because quite a few

Are quite frightened*

Jane demonstrated that it was alright not to have all the answers but her presence was important and just “being there”. Her natural caring instinct enabled her to walk alongside those she was caring for. The value of presence is an important aspect of care. A definition of presence by Thomas (2003) that I use in education sessions describes being there:

“The word of comfort and reassurance, the quiet “being there”, building up this sense of security for patients, comfort from the physical and emotional traumas and the support of someone acting as a companion on the journey – these are important aspects of care” (p.45).

Another useful definition of presence by Bornman and Brown-Saltzman (2001) describe presence as follows; Presence transcends role obligations and acknowledges the vulnerable humanness of us all....to be present means to unconceal, to be aware of tone of voice, eye contact, affect and body language, to be in tune with the patient’s message” (p.422).

*One man said
He was frightened.
He wanted his bed
put in a position ready to go.
He wanted to know
what was going to happen
We just don’t know the answers
but we can just give*

A bit of peace

Jane displayed a commitment and love for her work. She often went beyond the call of duty and just sat with people. She felt very comfortable sitting with dying people. In the study by Goodridge et al (2005) it was reported that “families

consistently voiced concern about their loved one being alone at the time of death” (p.230). Jane instinctively stayed with residents who were dying.

*Families can't always be there
all the time,
But knowing
They are not alone.
there's a lot stored
in there
That I think the flood gates open*

At the end of life.

*I know my presence
is welcome
I know they know I'm there.
in their last days
They still know
there's a presence there.
I know they can
still hear me*

*I massage their feet
I know they appreciate it.
Even if they're
not talking*

I know it's appreciated.

*There is a lot of anxiety
at the end
They're uncertain of*

*what's going to happen.
Some of them
even say that verbally.*

*You just reassure them that
they are loved and*

*Look behind the person,
That was a highlight
For me
In the course
That behind their disease
there is a person there
That we can make a
difference
to their life.*

*When I give out care
And can help someone,
Even if I can
make them smile,
That gives me
so much strength*

*I always felt put down.
I had no confidence.
None whatsoever,
But I'm the opposite now.
I was shy, I never spoke,
I'm the total opposite now.*

*I really do feel appreciated.
in the role that I am in now,
Within my own self,
With the residents
I make a difference
To them...in that way*

I feel appreciated

3. Turning Point

When I got help with counseling after my traumatic experience, I let a lot of stuff go cause I had the right channels to go through and the support so I know how I liked being treated. If you can treat other people how you like to be treated, and if you can show a bit of caring you get a better response.

There is a lady I have looking after. I don't think she has had much love in the marriage and she is talking quite a lot now so I just comfort her saying you are safe and you are loved and she quietens down and smiles.

Education made a lot of difference. One session in particular and I use this example to other people. One example you brought, you showed us photographs, one was a man and he'd had a stroke and he was in his wheelchair and you had a caption "I'm not a stroke victim, I am Mr, I am an airline pilot, I am a person in here" and then you went on to show a picture of a lady... "I am not this Alzheimer's person I am a person in here", "I am not the person in the wheelchair I am". To look beyond their disease.

It's a rewarding occupation to give something of yourself to make a little difference which we can do, with the education. I use it quite often. Those photographs just had an impact on me.

4. Caring Moment

Well that is their home and that's the place they're going to end their days so the least we can do is make them feel better. This one case a man was dying and the heating broke down in the night time and two carer's pushed him into the recreation room with the net curtains and it was warm and he thought he was home, he thought he was in his own lounge, he just was quite happy there and the sun came in.

As the throat muscles were the last to go, his daughter and I were there and it was like playing charades as he wanted to be understood. I went to the trouble to find out what he was wanting. And he said 'Eskimo pie'. So I rattled my keys like I was going to the shop and I ran to the kitchen and I said 'can I have a teaspoon of ice-cream in a cup' and I just put a bit on his lips because he wasn't eating and he had that taste of 'Eskimo Pie' and I just put a bit on his lips because he wasn't eating.

When I told my mother, she said 'well her mother did the same. She got the taste for peach and Mum rushed away and got her some. She said she just had a bit on a spoon.

So just little things like that."

5. Reflection

When I first met Jane she appeared to be a very self contained lady who always had a calmness and contentment about her. Her obvious pleasure at looking after the residents was portrayed in her sense of presence and in the way she went the extra mile for others and spoke caringly about what she had said or done to the resident. Jane was happy to share her life with me and talked of the different stages of her life and how situations forced a change in how she lived.

Unknowingly, Jane had made choices that were “turning points” in her life and resulted in a change of direction along her life course.

The traumatic experience Jane encountered made her value what she had and she felt empowered by the help she received from caring health professionals. It made her understand how past experience and how her early life influenced how she felt about herself. Jane disclosed that love and caring had not been shown to her in a physical way and she had no experience of closeness in her early years. Vachon (2001) notes that successful caregivers are often “wounded healers,” with wounds sustained either in childhood, adulthood or both. “One’s deepest wounds can become one’s greatest sources of strength” (p.658). Since becoming a caregiver Jane felt an overwhelming sense of belonging and expressed complete contentment with her life now.

Sarah

1. Life Story

Sarah has been a caregiver for 16 years. Sarah was the eldest girl out of 8 children and was involved at an early age in helping to bring up her younger siblings. She remembers her family never had any money but there was a lot of love in her house. At the age of ten she had to cook tea, sew for the younger children and always had chores to do.

It was Sarah's grandmother that had the most influence on the way she cares. She taught her how to cook and spent time with her. She "idolised" her grandparents and learnt at an early age about care, understanding and love.

Due to changes at home when she was about 14 Sarah took on even more responsibility. She married young and continued to be involved in the care of her younger brother. Sarah feels her role in life has always been to be there to give to people. She feels what she has learnt from her own life experience she can now give back to people who have also had hard times.

Sarah had always wanted to be a nurse but her parents could not afford to let her go nursing as they needed her to look after the other children. Sarah became a hairdresser and then was involved in bringing up her own children. She then worked for 10 years as a caregiver for Intellectually Handicapped Children (IHC) which she loved. That role also involved care of the elderly. After 10 years she "burnt out" due to the long hours. She continued being a caregiver in people's own homes. From there, for a change, Sarah went and worked in a factory which she hated. It was too regimented; no talk or laughter was allowed. At this point, Sarah realised she liked to be able to help people and felt this was her role in life. The factory work was a catalyst for change.

Sarah also described a "very bad experience" in her personal life a few years ago that made her change. This turning point in her life made her realise that "I don't let people walk over me now like I used to". Before this experience Sarah

had always felt inferior. She was afraid to say no to people and always did what was expected of her.

*I took charge, I had to take charge. First of all I had to take charge of myself.
I had to take charge of myself so I could carry on in life and do better for
myself first*

This experience made her a stronger person. By becoming stronger she felt better within herself which resulted in an increase in her self esteem. She became a more understanding and caring person as she became more confident. Due to this turning point in her life, Sarah now believes she has the understanding and respect for the people she cares for.

2. Poetic Condensation

*I'm the eldest girl out of 8
We never had a lot
But we had a lot of love
In our house*

*I always wanted to be a nurse
But mum and dad
couldn't afford for me to go
I had to help bring up
my last
four brothers and sisters
Mum had to work*

*The children were my life
as far back as 12 years of age
From there I got married*

*I had 3 children of my own,
Who I love dearly
I ended up getting a job with IHC
And was there 10 years,
Absolutely loved it
Looking after the elderly.
I've always looked after
the elderly*

*After 10 years I got burnt out
cause I worked hours
you wouldn't believe.
Then I went,
still care giving,
into peoples homes,
Cared for people*

In their homes

*I then worked in a factory,
Hated it
It was very regimental,
You weren't allowed to talk,
You weren't allowed to laugh
I like laughter,*

*To be able to talk to people,
To be able to help people
My biggest role is helping people
It's something
I enjoy*

Sarah's life course had been looking after people. From an early age long-term patterns within her family life has been embedded in her transition from one section of her life to another. Caring was integral to her life and without it her wellbeing was affected as illustrated by her unhappy time working in a factory. Sarah needed to care for people and made a choice to change direction in her worklife for her own well-being.

*What did I bring here?
I brought my experience
of having worked with IHC
Because they are
very difficult people sometimes,
But I feel
that in my role as a care giver*

I'm understanding.

*I understand the people,
I listen to the people
I get into their space.
I don't put my views
across to them
I actually get into their space
I think that is something
you really have to do
Especially with the people in here.
And I just love them*

To bits.

Sarah worked in a dementia unit. Her previous skills gained from working with intellectually challenged people meant she was comfortable in this area and brought with her knowledge and most of all, the art of caring.

When I first met Sarah she had attended the palliative care education sessions at the hospice and always contributed in discussion. It was obvious that she also mentored and supported her colleagues who had also attended the course. Her natural caring disposition appeared instinctive. Later when Sarah volunteered to be part of a special palliative care interest group, she showed she had a passion for working with the elderly. This group, as described in previous chapters was part of implementing the LCP into the facility where she worked. The education, both formal and informal created an opportunity for insight which was a turning point for Sarah. She finally felt valued.

*I was asked by a manager
if I wanted to do palliative care
She thought I had a flair for it
I said I'd be very interested.*

*I didn't know you
When I first met you
I thought you were
a very caring,
understanding person
By putting what you taught us across
You did it in such a way
that I understood it.
You didn't use big words.*

*You didn't use words
that I couldn't understand
And with the help of the group,*

*Because we worked as a group,
I felt that was just wonderful
Because we could all
put our ideas across,
whether they be good
Bad or otherwise
We suggested a palliative care box,
I thought*

That was just wonderful.

The palliative care box was an innovative idea that came from the caregivers. A box containing special soaps and creams, fresh pillowcases and duvet covers, soft gauze face cloths, mouth swabs, shampoo caps, aromatherapy, massage oils, and assorted music tapes was put together so that these items could be accessed readily if someone was dying. Previously time was spent looking for these items and often items caregivers wanted to use were not found. At every meeting of the special interest group, more suggestions were offered or the caregivers purchased items themselves and added to the box. These included a tea-set and china cups and saucers, a tea tray, vases, a bible, rosary beads and a book on different cultural needs. The contents of the box became the responsibility of the caregivers and a box was placed in each wing of the facility. I noted that the aromatherapy oils they had purchased were sometimes not appropriate or had the potential to be overused. An education session from the hospice aromatherapist was arranged which was well attended. Interestingly, each item in some way created an opportunity for education as to why this item was important and usually initiated a round of stories.

*The education
It gave me the insight
When a person is coming
to the end of life*

*How important
it was for them
to be treated the same*

*With dignity and respect,
which we do anyway
It just emphasised it
a little bit more,
Not to rush them
or anything like that.
To sit with them,
To listen to them*

*Because some of them
wanted to talk.
They knew they were going
and they wanted to talk.
So you could sit
and talk to them*

And listen

*To what they were saying.
it's taught me a wider variety
of caring and understanding.
I understood before
but it's given me
that wider expansion
of caring, understanding*

And love.

*Since I've been here
More so since I went
on the palliative care course
It gave me a lot of meaning
of how to treat the people
It's something
I thoroughly enjoy*

Been absolutely fantastic

*It made me feel
more part of the team
I've had some
responsibilities
given to me which
I thoroughly enjoyed.
I am actually helping*

With the doctors rounds

*I feel very valued.
It's made me think
I'm needed
just a little bit more
Because I've got that
little bit more extra
responsibility.*

*I'm not frightened
to ask questions*

*I'm not frightened
to put a concern across.
It's given me
more confidence.*

*Before I would stand back
and think well there's somebody
more experienced than me
Now
that thought
doesn't come into my mind*

*If I see somebody
in need I will go.
It's made a big
big difference
I think I bring
understanding and....*

My heart.

3. Turning Point

A few years ago I had a very bad experience which made me change where I had to change for myself and then for my changing for myself I became a stronger person. By becoming that stronger person I think I became a more caring person. It was many, many years ago now but I feel that I don't let anybody walk over me now like I used to. It's one of those things that I think because I had the experience that I did made me realise that I was not going to let anybody walk over me anymore.

I felt as if I had to please everybody. I didn't like confrontation. If I was told to do something I would go and do it because I was too frightened to say no but after this experience that I had no more; nobody tells me what to do because I don't feel anybody's got the right to tell anybody what to do in their life. They can suggest, they can ask but don't tell me and I will do whatever I can to help anybody. But I feel far, far better within myself of the experience I did have and I think it made me a better mother and a more understanding person as well.

I grew in confidence and never looked back. I was a very inferior person for want of a better word. I used to stand back and let everybody else do it and I'd have to be pushed to do things. And it did hold me back,.. it really did hold me back.

I took charge, I had to take charge. First of all I had to take charge of myself. I had to take charge of myself so I would carry on in life and do better for myself first.

It made it easier for me to do the job that I love.

4. Caring Moment

I had a man I was looking after ...it was in winter time and he was dying, he knew he was dying and he was cold so he asked me to put a beanie on him which I did and a scarf around. And then he said to me would you put your head on the pillow next to me. And I said of course I will. So I was sitting in a chair, I put my head on the pillow next to him, he held my hand and he says thank you so much. He didn't die that night, he died the following night.

And that made me feel so, so good that I could give him that, he needed that.

I just said yes that's fine and it wasn't the first time I'd done it. And he'd want to hold your hand which I would do and while I was holding his hand he was talking to me about the war and flying planes and then he'd drift off to sleep and I'd think oh well I can let his hand go now but no, as I went to pull my hand out he'd grip it even harder. He needed that human touch and that human touch..... I felt meant so much to him.

5. Reflection

Sarah cared for residents as she did her own family. This simple narrative conveyed a depth of compassionate humane response to a dying man. She was “at ease” with the moment and responded to a need that may well have been unmet if time or ‘presence” was not given. Sarah’s life experience and past activities were automatically assumed when caring for this man. Caring had provided meaning and continuity throughout her life course.

Nursing requires practitioners to care for and be responsive to other human beings (Kenny,2003). Sarah’s own reflection was that she had met a spiritual need of this resident. The trusting, empathetic relationship ensured that she was truly present at the time that he needed it. Goodridge et al (2005) endorse that the caring behaviours of staff are critical elements in the dying experience.

Mary

1. Life Story

Mary had always wanted to be a nurse since she was a little girl. She perceives she was very slow at school and “wasn’t very clever at remembering’. She was always too scared to ask questions. She was very shy and remembers there was no encouragement from home or school to support her.

When I look back now it’s quite sad. I would have loved to have done it (nursing) but didn’t push or anything. Yeah, it’s sad.

When it came to caring, Mary felt she was always loved but can’t remember ever having a cuddle from her mum or dad. Her father was always working. He worked nights so he slept a lot during the day. Her mother was not allowed to work but had support from an unmarried sister who lived nearby. Mary felt her mum was told how to bring the children up by her sister. This aunt had an influence on Mary’s upbringing. When Mary had her own children she didn’t know how to cuddle them.

At first I would find it hard to give them cuddles.

Mary worked in a shop for many years, got married, had children and worked several jobs in a supermarket and hospital cleaning at night. At a certain stage she felt unsatisfied and knew she had to get out. At the same time, Mary’s ex husband died of a brain tumor. This was a hard time for her with 2 teenage children. They were separated but had been together since school days so together for many years.

I used to take the kids up all the time, I never stopped the kids from seeing him. Watching him die of a brain tumor and seeing him in the last stages was hard.

She applied for a care givers course she saw advertised and from there came to work in an aged care facility. She speaks enthusiastically about her work and 'loves' it. She loves being with people, helping them. For the first time in her work life she feels valued. She was looking for something different and knew she could do this work.

I don't really know, I just wanted to do it. I think because I couldn't be a nurse, this was the closest thing I was going to get to be a nurse. Yeah, and I give little cuddles yeah. So different to what I grew up with.

Mary always felt shy, lacked confidence and feels she let herself down. She thinks she worries too much about others and has never considered herself as being important. She doesn't know why. The palliative care education sessions Mary attended gave her the confidence to participate and contribute to discussions and this was a turning point in her life.

I listened to what everyone had to say and maybe felt a bit more positive about myself and that I can do it and not put myself down and that sort of stuff. I never thought I would go as far as I have done.

Mary loves her work with the elderly and when asked what she brings to work everyday, to other people's lives she replies

Myself! And a smile ...I always go to the lounge and say good morning to everybody.

2. Poetic Condensation

*I went through college
My brain
wouldn't let me remember*

*A lot of things and I knew
I could not do it*

*I wasn't very clever
at remembering.
Wouldn't ask questions*

Too scared.

*No encouragement
from home
I look back now.
It's quite sad.
I would have loved.....
Didn't push or anything.*

Yeah it's sad.

*How did I learn to care?
I don't really know
I just wanted to do it.
I couldn't be a nurse
This was the closest thing
I always wanted to do it.*

*I worked for 18 years
in a shop
I knew I had to get out
So I went and
did a course
So I'm here now.*

I love it.

Just being with people,

Helping them.

This was a turning point in Mary's life when she made the choice to move on. She exerted control over her life for the first time and in doing so changed the direction along her life course. Mary had lacked confidence and had not ever pushed herself to make choices. Her social circumstances and upbringing had not given her any confidence or 'tools' to make changes. When introduced to education and ongoing learning, Mary initially still felt she was unable to contribute.

Mary had earlier mentioned that she felt as if her brain did not work when at school. On reflection the teaching style at that time did not accommodate individual learning styles. Mary received no encouragement from her home or school life.

When we first met it was patently obvious that Mary was very shy, lacked confidence and stood back. Yet she shared an empathy for the residents and a caring side that just accepted people as they were – no expectation. Initially Mary volunteered to be part of a palliative care special interest group. She stood back but as time went by she slowly began to contribute to discussions. The different approach to learning through sharing stories enabled Mary to understand that she also had stories to tell. This empowered her to feel good about the work she did. On reflection Mary recognized that she possessed skills pertinent to her role. This was another turning point for Mary as she now felt part of a team who respected each other's ideas. She felt listened to.

When I first met you

When you first came here

I thought

What have I got myself in for.

*It taught me a lot
I never thought
I would go as far*

As I have done.

*I listened to what everybody
had to say
Just listened to
everybody.
I feel a bit more
positive
about myself
That I can do it*

Not put myself down

*The palliative care course
at the hospice
That was really good.
I enjoyed it
Learning how to deal
with death
was probably good for me*

At the time.

*How different people die.
You know...
The different stages
when they are going.*

*The actual reality of death
People who were near end
of life*

*Nothing prepared me.
It's more doing.
I found the death part
quite hard*

To be able to deal with

Mary initially found it difficult to care for people who were dying. As time went on and with support of colleagues she found great satisfaction of being with people with whom she had formed a relationship. She was familiar with each resident, their likes and dislikes by virtue of their long-term relationship. Staff interviewed in a study by Goodridge et al (2005) reported that "the ability to provide excellent physical care of the dying patient provided the most personal satisfaction to them' (p.229).

*I do have the closeness
because you....
you really know them
You know them
as a person.
That's because they're people*

They are all people.

3. Turning Point

I had not made many changes in my life then someone close to me died. Just watching someone go through the last stages of life was really hard. Sometimes I had to just push myself cause I had to get through what I had been through so I had to really shut things out.

I have always been very shy and not very confident. My decision to change the course of my life came after this loss. I was working in a supermarket. I was "sick of it" and I made a decision to change the direction of my life. I attended a short caregiving course and went into a caregiving role as I thought it was something I could do after experiencing a loss. I initially found being with dying people stressful but nothing had prepared me for the actual reality of being with people who were dying. I realized it was more in the doing but found the 'death part' quite hard to deal with. There was somebody that Monday and she was dying and I just looked at her and I just walked out crying cause I knew. We knew she was dying but I so I didn't do her after that.

They were really good there they said I didn't need to do it, make yourself a coffee, which was really good.

Being involved in the palliative care education sessions and interest group changed things for me and increased my confidence in caring for the dying residents. I found the sessions 'really good' and enjoyed the sharing of information and hearing how others in the group dealt with similar situations and feelings.

Learning how to deal with death was also good for me at the time. How different people die. You know the different stages that they react when they are going. The palliative care interest group increased my confidence too. I listened to what everyone had to say and was able to participate and contribute. I felt more positive about myself and that I can do it and not put myself down any more. It made a big difference to me.

I quite often think about I'm happy where I am. There is a skill in looking after the dementia patient. I know I've done something. I just kept saying that 'you can do it..... and that you are looking after someone who is dying – the end of another life'. Education has really helped me.

4. Caring Moment

One man who knew he was dying and he wanted me to lay down on the bed with him and he moved over and we lay down on the bed together and he just looked up at the roof and I just talked to him. It made me feel special and maybe helping him try and get through the last part of his life. I didn't have to think about it, it was an automatic thing to do cause that's what he wanted, his final wishes. I'm glad I did it, I didn't have any regrets.

Sometimes if you're sitting on the chair and they say come put your head on the pillow, I'll just do that or hold their hand. Just being there. And them knowing that you're there, holding their hand.

The word of comfort and reassurance, the quiet "being there", building up this sense of security for patients, comfort from the physical and emotional traumas and the support of someone acting as a companion on the journey – these are important aspects of care (Thomas, 2003, p.45).

5. Reflection

On first meeting Mary, she lacked confidence and found difficulty in expressing her feelings. Her increased confidence through education and being involved in a team enabled her to feel good about her work and direct her natural caring to the residents she cared for. Sandford (2000) suggests "natural caring is a

spontaneous response, the motive to care arises on its own; it does not have to be summoned” (p.9).

Mary responded well to the group sessions through the sharing of narratives with other colleagues. The sharing of practice experience empowered her to explore and share her own feelings. Supportive relationships with colleagues when residents close to her were dying enabled her to feel valued.

CHAPTER FIVE - DISCUSSION

The discussion chapter captures my insights through a series of themes that arose from the whole project. The emphasis is on the insights that I have gained in this journey over time from the inception of my interest in addressing the issue of care of the dying elderly person.

Introduction

The purpose of this final chapter is to present the interpretations of the study, and to discuss how the life experience of caregivers, and the education that has been given does impact on quality end-of-life care for the elderly in ACF. The themes which have emerged from the overall project will be addressed in the discussion are initially presented in Table Two. My plan in this chapter is to present a focused discussion on each theme.

Table Two

Phase One:	Phase Two:
Interest: <i>End-of-life care for the elderly person.</i>	Interest: <i>The role of the caregiver delivering end-of-life care to the elderly.</i>
Question/Objective: To evaluate the introduction of the Liverpool Care Pathway for the terminally ill/dying phase in an aged care facility within.	Question: How does a caregiver's life experience influence the care they give to the elderly at the end-of-life and how does education influence the caregiver's well-being?
<u>Themes</u>	<u>Themes</u>
Relationships	Education
Complexity of Care	Life Story
Liverpool Care Pathway	Caring Moments
End-of-Life Care	Turning Point
Resources	Choices
Caring	Well-being
Teamwork	

Phase One Significant Project Themes

Relationships

There are several key aspects of relationship that I will address; firstly my relationship to policy and my gradual questioning of practice and secondly the development of collegial relationships. The importance of relationships and acknowledgement of expertise held by colleagues is paramount when working collaboratively between health care services. The development of this working relationship was one of the first steps I had to establish before embarking on this study.

The hospice I was employed at showed a commitment to providing equal access to palliative care for people regardless of disease or place of residence. This was consistent with the World Health Organisation (WHO, 2002) definition of Palliative Care and the New Zealand Palliative Care Strategy (2001). My role as the inaugural PCNSE was an exciting challenge as the main aim was to improve the integration of palliative care with other health services, and to increase health professionals understanding and application of the principles of palliative care. One of the key performance indicators of the local District Health Board is equitable access to palliative care services for all people who are dying. In my view access to palliative care depends on relationships between the staff working in ACF and the palliative care providers.

It was obvious from the beginning of my involvement as a PCCNS in the region that certain groups in society lacked expert care and the ACF had the greatest need of support from the specialist palliative care provider. My focus as a specialist palliative care nurse had been mainly with people with a cancer diagnosis. When I started this research study I deliberated carefully if the topic I had chosen would have influence on the future care of the elderly in ACF. I found I was becoming more passionate about the delivery of end-of-life care in ACF. Phase one of the project focused on my awareness of the inequality of care provided to the elderly compared to that offered to patients in hospice care

settings. I began to ask the question about equity and access to knowledge and resources available to colleagues, and specifically if people were receiving quality end-of-life care? In my role I had observed every day wonderful caring being performed by some caregivers being described as so called “mundane” care by others. Caregivers rewarded me with being witness to countless caring moments as they occurred. Hudson (2005) refers to the ‘ethics of the mundane’ which means that providing essential everyday care become an important ethical debate, if not provided well. The focus can then revert to what others think is a problem and sometimes the attention has been diverted from the most problematic area.

The more I was involved in the education and informal meetings with caregivers, the more I reflected on what was important to patients and families at the end-of-life. Although my role as an advanced health care professional involved disseminating knowledge through education informally and formally, it was the natural caring by caregivers that enhanced the quality of care given to the resident. The culture of care in an ACF was one that had to be understood. Long term relationships between staff and residents was an important factor to take into account, as often the professional and personal relationships became intertwined. ‘Special relationships’ are a facet of palliative care to be fostered, because of the positive effect that they have on those cared for (McKinlay, 1998, p.188). This is very relevant in ACF where the residents and staff have developed a long term relationship, sometimes over years. In her unpublished thesis McKinley (1998) describes a circle of care which requires “... detailed attention to staff selection and support mechanisms such as ongoing education, mentorship, role modeling, clinical supervision, debriefing, counseling, monitoring by clinical leadership, peer support and time off to attend funerals” (p.188). I agree that all the above suggestions are valid and extremely important when involved in the care of vulnerable people at the end-of-life. Unfortunately currently in New Zealand most of the above are not feasible in the aged care setting. That is not to say that these goals should not be strived for as policy;

and minimally it could be possible for management support to be available in regular debriefing sessions to support special relationships.

Based on these initial insights, I felt affirmed in the collaborative approach I had taken with the ACF. I would visit all the facilities after the initial introduction, for a cup of tea and chat with all staff including the caregivers. The chat was directed at finding out about the families that they were involved with as they cared for clients who were dying, and making a connection with the care givers as if we were equally involved in providing care. In this way I was able to personally invite and then encourage them to attend education sessions. It was important to establish relationships across the whole team in the care setting; this included the caregivers, registered nurses, the managers and the doctor as they worked as a team. It took multiple visits to develop these relationships and gain trust with other professionals. I would articulate the palliative approach to care of the dying and indicate that the collaborative approach with the Hospice could only enhance the care delivered to the residents. I enjoyed this ongoing conversing about the principles and practice of palliative care. In my view it was through these conversations and connections that we became engaged and trusting links were established.

Complexity of Care

The difficulties in elder care settings have been described in an opening chapter and concern such as increased complexities of patients with co-morbidities, lack of access to medical support out of hours, lack of trained staff, lack of education, lack of funding and lack of understanding by society as a whole. These concerns are confirmed on many occasions in the literature (Wowchuk, McClement & Bond, 2006; Hodgson & Lehning, 2008). The role of the unregulated healthcare worker has been discussed and highlighted by Smith, Kerse and Parsons (2005) who comment that healthcare assistants (caregivers) work without the obligation imposed by registration or enrolment, without a

professional code of ethics, and without professional codes of practice enforced in courts of law. Quality of care is largely dependant on caregivers self awareness of what is required as they deliver the majority of care. Most knowledge is gained “on the job” and therefore relationships with a mentor, for example the registered nurse is extremely important. I was aware that the establishment of relationships and palliative care education of this group of caregiver’s was essential.

There has been a common assumption that ACF are seen as the less desirable work settings or the ‘Cinderella of nursing’ (i.e. the least desirable place to work); the place you work if you are unable to get work elsewhere due to home commitments, or lack of expertise. This assumption was contrary to what I observed. The diversity of care work and the government and societal expectation, that ACF must now provide care for people with multiple co-morbidities is a reality. Wowchuk, McClement and Bond (2006) report that nursing homes (ACF) must now provide care for people admitted under a broader range of circumstances. The main emphasis for residents has been on maintaining life but with the changing profiles of the aging population, older people are entering ACF at a time when they require more intensive care than previously. In a study by Payne, Hawker, Kerr, Seamark, Roberts, Jarrett, and Smith (2007) it was noted that the labour-intensive nature of the work, caring for so many older people with the complexity of their co-morbidities, made work demanding. One registered nurse described this as ‘soul destroying’ hard physical labour (p.120).

One issue that influences the culture of care in ACF is the level of education of the staff. Hodgson and Lehning (2008) state “that although nursing staff in long-term care are at the forefront of end-of-life services for individuals, especially those with dementia, they have not received the training to enable them to adopt palliative care practice” (p.43). Payne et al also observed “some training in palliative care was provided by hospice nurses who had little understanding of work pressures in the aged care environment” (p.122). For this reason it is

vitaly important that palliative care educators from a hospice setting provide education that is flexible and accessible to staff in the aged care setting.

Liverpool Care Pathway

The implementation of the LCP in an ACF was an effective medium for me to be involved with an ACF, and to be seen as part of a team rather than an outsider. As mentioned earlier in the discussion on the LCP, the establishment of relationships with staff is key and anchors the process of developing discussions about care which includes that of the dying person. It was the involvement of the caregivers in these discussions which opened the way for a schedule of organised education sessions.

The analysis of the focus group feedback and the caregivers interviews clearly showed that with a plan of care in place a calm atmosphere, an organisational preparedness and 'smooth sailing' was more likely to be ensured for residents at the end-of-life. Although the main purpose of implementing the LCP was to have a plan of care in place, the project showed that this played only a small part in the study outcome. The development of skills in assessing and team work and valuing of staff involved had greater impact on all residents, not just those who were dying. A knowing 'how' and 'why' changes occurred generally in the process of dying for an individual was valuable and changed the direction of care away from the task to the caring of the person.

The specialist interest group that evolved and continued from the LCP project was the catalyst to organisational change and created significant turning points for some of the caregivers. The caregivers who joined the special interest group became more confident as they reported back to the group and shared personal experiences that became teaching moments. It was articulating reflections in conversation, exploring them in training sessions and continuing to explore the framework of caring for the dying, which illuminated the everyday learning from

practice that clarified meaning for them. Benner (1984) suggests that knowledge is often buried in practice and it is in the story telling that can often highlight hidden nursing practice. I began a journey which has illuminated what I already witnessed.

End-of-life Care

I had observed that some of the caregivers sat with people who were dying in their own time and came in on their days off to be with residents. Due to the long term relationships that had been established, the staff became part of the resident's extended family to the extent that it never occurred to the care givers not to stay with residents who were dying. This care came from within the caregiver as a person and was not seen as a duty, rather as part of a caring human connection that transcended all other considerations.

Increased demands occur in the team when someone is dying and this was acknowledged by including extra nursing care, time and supporting family (Komaromy, Sidell & Katz, 2000). This has been discussed and highlighted by Lefebvre-Chapiro (1998) who noted that each elderly patient receiving palliative care requires around six hours of high-quality care every day. An ACF is the resident's home and familiar surroundings and staff are an important factor at end of life.

The caregivers experienced a change in their practice in the care of the dying after the education sessions and focus group. They felt supported as they knew the language to use and how to talk with relatives. The education sessions had given them confidence, empowered them and had been a turning point for them in the way they now perceived themselves. It was clear during the project that staff must be equipped with sufficient resources in the team, time and knowledge to address the needs of the dying person and their family adequately. The caregivers referred to the extra time they were given through the end of life funding to sit with dying residents and give individualised care. This was mentioned several times as a 'wonderful' thing to be able to do.

It would be accurate to state that all staff were involved in the LCP education but the caregivers involved in the development of the culture of care of the dying were those who had a specific interest in palliative care. I had observed these staff as being open to the LCP education as a whole and they sought ongoing discussions with me that enhanced their learning. These caregivers became special, of course, in my eyes as we were learning how to implement change in the organisation.

One challenge of sustaining new practice in this aged care environment was the high turnover of staff. Introducing them to the new concept of care can take time until new relationships are built. This is something to consider but I believed the caregivers were passionate about ensuring they could put into practice all they had learnt and therefore spoke about staff changes as a challenge openly. We discussed this as being what was occurring in their work setting and a factor that we had all to take into account.

In summary in discussing the nature of *relationships* as a theme in the project, I have endeavored to emphasise how significant it proved to establish good relationships with all people involved in the facility and beyond with the care of the elderly at the end-of-life. Caregivers are a significant group of healthcare workers who work most closely with the dying resident and form close relationships with residents up until their death. They have the ability to influence the quality of care given to a resident not only whilst living but also when dying. I am drawn to the writings of Rosalie Hudson, who is the director of nursing at Harold McCracken House, in Melbourne, Australia. Hudson states that “residential care is not ‘an end’ but another stage in a life. A stage where life can flourish right up to the very end” (Hudson, 2001).

“I see it as a very distinctive opportunity to bring out the best in relationships between nurses and older people ... to see how we can make their lives flourish even in their most extreme frailty. You need other people in order to flourish when you've lost the capacity to move, to

... speak to articulate your needs... you need other people to understand - as far as we ever can understand what another person is going through – from their side what it is to be in that particular situation. Personhood, the dignity of being human, is conferred by one person upon another (Hudson, 1999).

I consider that the caregivers who were interviewed each displayed the essence of this message in the practice I observed.

Resources

Meetings were held with managers and key people to discuss areas of concern relating to the barriers that they perceived in delivering quality palliative care. Internal and external factors commonly prevented the sector delivering quality end of life care. The managers were committed to providing quality palliative care and many had a strong desire to deliver excellent ongoing care for their residents but were restricted by lack of staff, lack of time, lack of access to medical services and lack of ongoing regular palliative care education (Personal Communication, 2007). Often patients were admitted to secondary level of care simply because there was some, if not all of the above criteria. For example where a doctor was not available to visit a person in the facility it meant that according to rest home regulations that person must be transferred to a facility where they could be medically assessed. This of course had led to many residents in this region being taken from the facility by ambulance to an emergency department to be assessed by a doctor in this setting.

Over time my approach to change this pattern was to address the facility staff as a team and acknowledge my involvement was to be supportive of the team which included supporting improved relationships and liaisons between hospice and ACF. This enabled ways to be developed of addressing the problems they identified. At one of the early meetings with the managers, we talked about what

was the main reason for admitting people from ACF to hospital at the end-of-life. It was identified that lack of 24 hour medical cover, lack of staff and lack of onsite medication were the main problems. I identified that the Liverpool Care Pathway provided a document tool on care of the dying which was gaining international recognition as a way to provide quality care at the end-of-life. This end-of-life plan of care had the potential to reduce the number of admissions of elderly residents to hospital in the dying phase of an illness. Managers acknowledged that often the resident died in the emergency department or soon after admission into the medical ward.

Inappropriate admissions to secondary care services are not only costly but a source of distress to the patient, family and whanau and staff. The care of the dying can become “medicalised” and expensive instead of a natural peaceful event. This problem was not only a local issue but has been highlighted in the international literature. Katz, Komaromy and Sidell (1999) state “that considerable savings could be made if older people were cared for outside the acute hospital setting when terminally ill” (p 64). The delivery of good palliative care to the patient at end-of-life can improve the quality of life for dying residents without the cost of more expensive interventions such as hospital stays (Buchanan, Choi, Wang & Huang, 2002).

Caring

In this project all participants portrayed caring behaviour to residents who were dying. This observation is recognised in other studies which examined the perspectives of families, nurse and caregivers (Goodridge, Bond, Cameron & McKean 2005). They claimed that caring behaviour was central to the dying experience and encompassed a wide range of activities. The caregiver’s intimate knowledge of the residents provided casual assessment of knowing when something different was happening, without the knowledge of in-depth

end of life assessment. This knowledge is crucial in the intimate care of the dying resident.

The value of presence was observed and referred to by the caregivers. This was acknowledged by three of the caregivers and something they felt comfortable with. Mary had not felt the same before attending the education sessions but became more confident with being part of a group and sharing stories. During the project she began to feel at ease with people who were dying but knew when to ask for help if she felt she was not managing. The ability to quietly 'be there' was viewed by all caregivers as natural. They did not have to think consciously about it. This being present and offering care from one human being to another as a natural phenomenon of empathy is the aspect of care that underpins the palliative care principles and is considered to address the psychological and spiritual dimensions of care.

The Alberta Palliative Care Handbook (2001) states that "the essence of spiritual care is "being present" for people as they confront suffering and struggle with spiritual questions. The foundation of spiritual care is the establishment of a trusting relationship" (p.2). Suffering may not be understood or interpreted in everyday care but as illustrated in Sarah's story when she sat with a man and at his request put her head on his shoulder. This simple caring act allowed him to share his story and go back in time to talk of fighter planes in the war. This unspoken permission revealed unknown suffering and in my interpretation thereby facilitated a peaceful death.

Caring in the workplace was spoken of often by the caregivers I interviewed in the project. It appeared to be a central part of practice that was considered to occur naturally and instinctively. I had observed on many occasions what I considered to be the gentle moments of a caregiver with a resident. On one occasion the staff in a dementia unit were trying to have their lunch in the dining room. It was Mother's Day and two staff members had not turned up for work that morning. Families were coming in to take their mother out for the day and

pressure was on the remaining staff to have residents ready. The staff worked closely together to ensure everyone was dressed, and looking their best. The day was still made special for the residents who did not go out. It was half past two in the afternoon when I called in. The two staff members I had come to see were sitting having a cup of tea. On either side of them were residents who were also dressed up for the day. Old time music was playing and the staff, although talking with me, continuously interacted with the residents. One was holding a resident's hands and although not able to speak, the resident clearly was enjoying the moment. This activity was including the resident in the moment. The music was alluded to and often a short burst of song, reminiscing with the resident as to where they might have been when they first heard the music. All this may sound simple but to me these were the caring moments that are immeasurable, intense and central in the art of caring. Lichter (1987) talks of "total care". An essential part of this type of caring is communication.

It is more than words. It involves the communication of caring, understanding, respect, support, reassurance and continuing availability. It is the sharing of a human relationship and a commitment to the welfare of the patient and his family in it's every aspect (p iv.).

Caring as expressed by the caregivers that day was visible but unspoken.

Teamwork

A palliative care interest group was formed as a result of advancing the LCP project along and was known as the Liverpool Care Pathway Focus Group. Meetings were held fortnightly.

The purpose of the meeting was to review the requirements of the pathway documentation and to answer any questions as to what was expected of the members, not only as a group member, but as individuals working as part of the focus group. These meetings became the strength of the project.

Although not part of the original plan to implement the LCP, due to ongoing staffing issues within the facility, these meetings formed a significant part of the education, ownership and success of the project. The carer's reported back each week on who was on the LCP, what happened, what they had learnt and education sessions relevant to their needs were arranged. Issues impacting on care were discussed and solutions, if possible found. The hospital manager, registered nurses, education and quality co-coordinator and the caregivers formed the group. A team atmosphere developed and a coming together of staff as a team was powerful.

It is important to acknowledge that there were difficulties which were often encountered in delivering education to caregivers due to lack of staff, unaware that education sessions were being offered, and not being released from work time to attend. There were occasions when caregivers attended education sessions in their own time and at their own cost. Due to the low wages paid and having to provide for families, it was not possible for some caregivers to attend education sessions even though they were keen to do so. While the caregivers in this project had limited education and theoretical knowledge in the nursing context, their life experience was a valuable source of knowledge (Ward & McCormack,2000). Their "knowing" how to care had either been instilled in them from their home life experience literally from birth or had been developed through their life course. The narrative depicted through the poetic condensation identified common themes relating to the choices caregivers made when education was offered to augment their own sources of knowledge.

Phase Two Significant Project Themes

Palliative Care Education Sessions

The palliative care education session as described in Chapter Two formed the beginnings of addressing the palliative care educational needs of the

caregivers. The literature supports the view that education is essential to enhance and provide that care (Froggatt, 2001). I regarded education as the catalyst for change in the level of knowledge of the caregivers and in the awareness of the team in these settings as to what care was necessary for people who were dying. The observation that caregivers gained confidence and increased job satisfaction through the informal and formal education received became evident. The caregivers in this study illustrated many times that they were adept at providing quality care to the residents which was generated from their reflections on what they considered to be appropriate through their own life experience. Caring concern was considered by staff and caregivers before the education sessions to be a natural and instinctive gift and was identified as “being” there for residents. The understanding of care of the dying person as having distinctive needs was minimal.

These factors are obviously relevant to consider but no more so than the thoughts and experiences of the caregivers. This area had not been given attention. My thoughts when working with the caregivers was to find out what attributes they considered were important in caring for elderly vulnerable people. This information gave me a starting place to plan what education could be considered useful for longer term strategic development of future workforce.

Life Story

Daaleman and Elder (2007) identify life course principles which direct attention to individual choice and decision making. In the caregivers stories and my attempt to identify the essence in the poetic condensation, they illustrate how throughout their lives, many different moments have influenced their choices and decisions. In the analysis of the caregiver individual stories, an understanding was gained of how their life course reached turning points. They revealed how through these moments or identified sentinel situations, or through education received, the direction of their lives was actually changed.

Jane had shared the story of her dramatic life-threatening experience when she consciously made a decision to care for people. Sarah's experience was a situation where she also made a conscious decision to take charge. In doing so she became a more caring person. Mary said she had no confidence but with mentoring and being part of a team she understood that she had as much to offer as the others and began to feel empowered and valued. Margaret identified several moments in her personal and professional life when she had sought help which enabled her to continue in the work that she loved. Her decision to seek help when needed and discussions at home with her family impacted on her own well being in both her home and work life. These changes also occurred within the education sessions as caregivers began to understand the dying process and why changes were occurring. As a consequence of the education they were no longer afraid to be with dying people and also gained confidence to support relatives, to be with family as they were dying. They also encouraged active participation in the care if they family so desired.

There were significant changes caregivers made to their practice and understanding of the process of dying, through education. These changes in practice created improved job satisfaction through being valued and having an increased knowledge.

The opportunity to share the narrative of their own story created a sense of self belief and value in the work they did. This is reflected in the stories and trust given to me when they shared very personal parts of their life. By examining their entire life course as they shared their life story the caregivers were able to reflect on the experiences and environments that shaped their development. They recognised that different situations or experiences had greatly influenced who they were and how their choice of work now had in some way been influenced by changes in their lives.

Caring Moments

Caring moments have featured prominently during this project. Caring moments obviously occur daily in interactions between resident and caregiver. Many are not even noticed but equally a caring moment is often shared with others and in doing so the fabric of care and enjoyment in being in relationships is cemented. The narrative of the caring moment is an approach to reflection on practice and is a way that most people can understand. In the telling of stories for purposes of teaching the LCP, I created an opportunity for the caregiver to understand and realise that they too had a story to tell. Often the stories were intended to make sense of practice and also to acknowledge the experience of the individual and others as a team who shared their work story. Ghaye (2000) explains as follows:

When a professional, either wittingly or unconsciously, is the architect of a caring moment it is probable that such evident concern is the result of a cognizant adherence to a consciously espoused set of personal and professional values. Such care reflects a genuine professional commitment to living out one's values in one's workplace (p.35).

I consider that throughout this project the caregivers exemplified many caring moments that echo this statement.

Turning points, Choices and Wellbeing

Turning point as described by Daaleman and Elder (2007) are "individual or institutional sentinel moments that result in a change of direction in one's life course" (p.87). In the life stories, the caregivers all pointed to a time in their own personal life that resulted in them taking a new direction in life. The palliative care education they received and their inclusion in the implementation of the LCP resulted in turning points for all of the caregivers. The increased sense of

value, contentment, confidence and an awareness of being 'at ease' with dying people, created an increased sense of well-being and job satisfaction. Well-being was described as "I love my work"; "I look forward to coming to work"; "I love the elderly"; I couldn't be happier". This sense of satisfaction and well-being has been well illustrated in the section on life story.

CHAPTER FIVE - CONCLUSION

In this project I have endeavored to put forward a case to understand and value the work of the caregiver caring for the elderly at the end-of-life. With the aging population and increasing complexity of care of people admitted into ACF, the characteristics of dying residents who require palliative care is one of high dependence. Therefore ACF play an important part in the provision of palliative care for dying people. As the main providers of “hands-on” care” it is of great urgency that the caregiver role is recognised as an essential component of the healthcare team. The life experience of the caregiver is worthy of acknowledgement and development. This source of knowledge has the potential to enhance the care given to elderly at the end-of-life if investigated and respected. It is essential that this group of workers are supported, valued and prepared for the sensitive, compassionate and professional care that they are expected to deliver.

Regardless of how palliative care services are formed, effectiveness in the delivery of the service relies on a trained staff that is educated in palliative care. Education is the key to the delivery of high quality palliative care but the question of who pays for education in nursing homes is one of much discussion. The increased confidence gained by the caregivers who showed an interest in palliative care education was evident in this project and in fact is evident after any education I have offered. This expressed desire for education and ability to synthesize knowledge by caregivers needs to be recognised. The affirmation by other healthcare professionals of the caregiver’s capacity has the potential to reframe the service vision and ultimately significantly improve end of life care.

Government and policy makers are faced with the challenge of planning future health needs and care of the elderly and this must include a more detailed review of the role of the unregulated worker. Human resource planners in healthcare will be forced through outcome measures that are integral to the implementation of the LCP. In the long run such measures will turn the tide and

their attention to the growing demands of caring for the dying and the elderly. Since there is an organizational solution, I consider that services will be more amenable to identifying the resources to support education for the staff.

It is against this background that I make the following recommendations.

Recommendations

In order to identify and evolve a vision for the development of palliative care of the elderly in our region, I established a preliminary set of goals; the first being to reduce the number of elderly people being transferred to hospital just before or during the time when they were dying. This thesis describes a series of steps that have been taken that have been built on this vision using a series of events:

1. The caregiver's role should be regulated and recognised as an essential component of the professional healthcare workforce.
2. Target local Aged Care Providers, District Health Boards and the Ministry of Health to promote the compulsory attendance of all caregivers at a palliative care course as part of their employment.
3. Funding to be made available from the Ministry of Health to facilitate this educational initiative. Palliative Care education to be delivered as a unit of learning and attended as part of the orientation to the role. Ongoing discussion and support groups could be established to offer annual educational meetings and ensuring new palliative care knowledge is transferred to caregivers.
4. "Hospital" level care to be renamed unless access to twenty four hour medical cover and medication available at all times. The title of hospital depicts a service that has resources and access to continuous medical cover. This title can be misleading to the general public and indeed to the

many politicians who I feel do not truly understand that most ACF do not actually manage to offer this service. Therefore an expectation is placed on aged care workers to deliver the same care as in a public hospital. This is not feasible.

5. Inequity is a serious issue threatening aged care facilities. A recommendation would be to increase pay rates of caregivers. This would reflect the value placed on the role and would attract people to a role where education is encouraged and available.

This project depicted the experiences of a small number of caregivers. It is important to note here that further research is required to expand on these findings. The caregivers I interviewed had a special interest in palliative care and expressed the desire to further their understanding of the people they cared for. They portrayed the characteristics that should be considered when employing people for the role as a caregiver. It is therefore essential that we pursue evidence to support the findings of this project that education can provide the necessary skills and understanding required to deliver quality end-of-life care.

Summary

The life experience of caregivers can influence the care they give to the elderly at the end-of-life and this study has revealed that an educational opportunity has impacted on their own well-being. The narrative methodology using life story informed by life course was found to be an effective methodology in drawing out the personal experiences and life stories of the caregivers. The analysis revealed insights into the way caregivers can provide and influence the care they give. The poetic condensation of the caregivers' interviews revealed the essence with absolute clarity of what I had hoped to convey. It was in the

sharing of their personal accounts and challenges that the care givers themselves were able to make meaning of their work experiences.

While I set out to discover how caregiver's life experience can influence the quality of care they give to the elderly at the end-of-life, I had little understanding of how life experience shaped that care and how turning points in peoples life inspired them to make changes that affected their work life and their well being. The results of this project illustrate the need to value the work of the caregiver in ACF and to acknowledge the worth of the rich experience they bring from their own life course. This experience needs to be further developed by providing palliative care education to enhance compassionate care of the elderly at the end-of-life. Ongoing support and palliative care education is necessary to implement changes in practice.

Isolation and loneliness of the elderly in ACF can be exacerbated if time is not available for staff to be involved in all the principles of palliative care. The caregivers, as illustrated in their stories and response to education given, have the ability to convey these principles within caring moments as demonstrated in this project.

Quality care of the elderly at the end-of-life can become a societal issue if the reported problems and issues of unregulated and underpaid care workers are not addressed and caregivers valued for the work they do. This issue has the potential to devalue the elderly in our society through a loss of dignity and through poor care at the end of life. I believe caregivers should be regulated to maintain integrity and give honour to the work they do.

Finally, I wish to express my deep gratitude to the caregivers who so generously and freely shared with me stories of who they are and how compassionate care is given instinctively to the elderly at the end-of-life. Although this thesis is based on a small project, I have deliberately directed the discussion in the thesis away from funding and figures toward life story and life journey stories to capture glimpses of how care is really delivered in ACF. My

hope is that in the future planning of the aged care workforce, consideration is given to the human act of caring and such caring is viewed as an essential component of end-of-life care.

Postscript

The following abridged letter to the President of the United States in 2005 epitomises to me the current issue we in New Zealand are beginning to be faced with.

“American society is aging—dramatically, rapidly, and largely well. More and more people are living healthily into their seventies and eighties, many well into their nineties. With birth rates down, with the baby boomers approaching retirement, we are on the threshold of the first-ever “mass geriatric society”. The fastest growing segment of our population is already the group over 85. Historically speaking, it is the best of times to be old.

Yet the blessings of greater longevity are bringing new social challenges. Although people are living healthier longer, many are also living long enough to suffer serious age-related chronic illnesses, including dementia. Already millions of American families are struggling nobly to provide steady and demanding long-term care for their incapacitated loved ones, often with little respite or communal support, usually for many years. Yet precisely as the need for caregiving raises greatly, the number of available caregivers, both professional and volunteer - is dwindling. We appear to be on the threshold of a crisis in long-term care.

This concern takes many forms-economic, ethical, social, and civic, and it promises to loom large in our private lives and public debates. Many of the questions center around caregiving: Who will need it? Who will do it? Who will pay for it? And perhaps most importantly, what kind of care is owed to those at the end of life? As a society, we have not yet faced up to this difficulty, especially in its human dimensions.

We may face a genuine caregiving crisis - with more needy individuals and fewer available caregivers, with growing costs of long-term care and fewer

workers to support social programs, with longer periods of diminished function.

Much caregiving involves hard physical work; it involves being sensitive to the needs of people who often cannot make themselves understood; it involves many tasks that individuals would not likely choose for themselves, even if they perform them with great equanimity.” (Kass, 2005).

The role of the caregiver in ACF in New Zealand is equally one that must be recognised and valued. There is an urgency to do this sooner rather than later. If we want good caregivers, we need to honor and reward caregiving, rather than seeing it as unskilled or undignified labour. This is a moral challenge as well as a social and economic one.

At the beginning of this thesis I outlined the circumstances that led me to investigate the role of the caregiver in the delivery of quality end-of-life care to residents who were dying in ACF. My interest was from the perspective of a palliative care nurse who had had the privilege to deliver the gold standard of end-of-life care (Thomas, 2003) to dying people in a hospice and I had an unease whether that same level of care could be delivered by an untrained, unregulated workforce in an under resourced sector of healthcare. I sought to explore how the caregivers own life experience could influence the care they gave and how education through the implementation of the LCP and education could influence their own well-being. A key feature of the LCP is its potential to empower generic health workers to deliver optimal care to residents who are dying. In the postscript I am without doubt that it is an organized fully resourced education programme for caregivers that is essential to turn that potential into a reality.

APPENDIX I



Central Regional Ethics Committee

Ministry of Health
10th Floor, 180 Molesworth Street
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2360

30 January 2006

Ms Kate Gellatly
Te Omanga Hospice
136 Woburn Rd
Lower Hutt

Dear Kate

GEN/05/12/091 - TO EVALUATE THE INTRODUCTION OF THE LIVERPOOL CARE PATHWAY FOR THE TERMINALLY ILL/DYING PHASE IN AN AGED CARE FACILITY WITHIN THE NEW ZEALAND CONTEXT

Ms Kate Gellatly
Te Omanga Hospice

Thank you for your letter of 26 January 2006 responding to the points raised in my letter to you of 21 December 2005. As all outstanding issues have now been satisfactorily addressed, the above study has been given ethical approval by the **Central Regional Ethics Committee**.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Final Report

The study is approved until January 2007. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely



Claire Yendoll
Central Ethics Committee Administrator

Email: claire_yendoll@moh.govt.nz

APPENDIX II

Information Sheet Phase One

“To evaluate the introduction of the Liverpool Care Pathway for the terminally ill/dying phase in an aged care facility within the New Zealand context.”

This study will be conducted by the Te Omanga Hospice Palliative Care Nurse Specialist Educator (PCNSE) in collaboration with the staff of the xxxxxx facility, Lower Hutt.

The purpose of the study is to ascertain whether the introduction of the Liverpool Care Pathway (LCP) will impact on the quality of palliative care provided in an aged care facility in New Zealand. The LCP is becoming internationally accepted as a safe and reliable tool to guide the application and evaluation of care received by dying patients. This research intends to explore the applicability of the LCP in the New Zealand context. The results of the study may provide the impetus to promote the use of this tool to other aged care providers, hospices and public hospitals in New Zealand.

Study Procedure:

This will involve a focus group meeting to be held at an agreed venue, where the staff will be encouraged to discuss the usefulness of the LCP, benefits to patients, families and staff and ease of use.

Consent and confidentiality:

Consent for staff participation in the study will be obtained from the Management of xxx to ensure that no staff member is harmed or disadvantaged in their future employment as a result of the research.

Anonymity of patients' records and confidentiality of staff contributions in all drafts and in the final report is assured. At the completion of the study all research data will be destroyed.

If any issues arise, staff members may contact Kate Gellatly, PCNSE, at Te Omanga Hospice to discuss same.

APPENDIX III

CONSENT TO PARTICIPATE IN THE STUDY – PHASE ONE

TO EVALUATE THE INTRODUCTION OF THE LIVERPOOL CARE PATHWAY FOR THE TERMINALLY ILL/DYING PHASE IN AN AGED CARE FACILITY WITHIN THE NEW ZEALAND CONTEXT

RESEARCHER/INTERVIEWER: Kate Gellatly, Palliative Care Nurse Specialist Educator, Te Omanga Hospice, Lower Hutt

TIME AND PLACE OF INTERVIEWS: Convenient to the participant.

PURPOSE OF THIS PROJECT:

The purpose of this study is to ascertain whether the introduction of the LCP will impact on the quality of palliative care provided in an aged care facility in New Zealand. The LCP is becoming internationally accepted as a safe and reliable tool to guide the application and evaluation of care received by dying patients. This research intends to explore the applicability of the LCP in the New Zealand context. The focus group meeting will inform the research group of the appropriateness of the tool and its ease of use.

There will be significant impetus to extend the application of the LCP to other aged care facilities and to public hospitals throughout the country if the research demonstrates an improvement in the quality of care, thereby improving the universal provision of care to the dying. Secondary to patient care and family support, but no less important, is the confidence the use of the tool may offer staff. Evidence exists of the stressful nature of working with the dying patient and their family so any means of minimising this stress will benefit the carers' involved. In an environment where professionally qualified nurses are at a premium, a clearly documented pathway may remove some of the stress for care assistants who provide the majority of care in aged care facilities.

PARTICIPANTS COMMITMENT IN PARTICIPATING IN THE STUDY:

You are invited to meet with the researcher at a focus group meeting to discuss the implementation and application of the Liverpool Care Pathway in your facility. This semi-structured interview will be audio taped and transcribed. The audiotapes and transcriptions will be locked away when not in use and will be destroyed at the end of the study. Your participation in the study will have no detrimental effect on your employment within the facility and you may withdraw at any time if you so wish. Anonymity of participants is assured in the research reports and publications.

INFORMATION DISSEMINATION:

The research findings will be presented in the first instance to Woburn Elderly Care staff for comment and/or correction, prior to wider dissemination. Thereafter the research findings will be presented to:

- Ø Staff of xxx and Te Omanga Hospice
- Ø The Grande Round at Hutt Hospital.
- Ø Nursing Research Day at Whitereia Polytechnic, 2006
- Ø Hospice NZ Conference, Dunedin, 2006.
- Ø Gerontology Conference.

Research findings will be offered for publication to:

- Ø *Whitireia Nursing Journal*
- Ø *Nursing Praxis in New Zealand*
- Ø *The European Journal of Palliative Care*
- Ø *International Journal of Palliative Nursing*

STATEMENT BY PARTICIPANT:

“I have read the information sheet and any questions have any been answered to my satisfaction. I understand that I may ask further questions at any time.”

“If I agree to participate and understand that I have the right to withdraw from the study at any time.”

“I agree to contribute to the focus group discussion on the LCP on the understanding that my identity will be protected.”

“I agree to respect the opinion of all other participants during the meeting and maintain the confidentiality of all discussion material.”

I AGREE TO TAKE PART IN THIS STUDY

Signature of participant: _____

Date _____

APPENDIX IV

**TO EVALUATE THE INTRODUCTION OF THE LIVERPOOL CARE
PATHWAY FOR THE TERMINALLY ILL/DYING PHASE IN AN AGED CARE
FACILITY WITHIN THE NEW ZEALAND CONTEXT**

This is to certify that I

NAME

ADDRESS

.....

.....

.....

I am the transcriber for the above-mentioned research study

I understand that the information contained in this study audio tapes, I am to transcribe is to be kept confidential.

I agree to maintain confidentiality by not disclosing any aspects of the audiotapes or typed transcripts with any other persons at all times other than with the researcher.

Audiotapes, transcripts and computer resources will be returned to the researcher as soon as they are finished with.

Date of2006

Signature

APPENDIX V

TO EVALUATE THE INTRODUCTION OF THE LIVERPOOL CARE PATHWAY FOR THE TERMINALLY ILL/DYING PHASE IN AN AGED CARE FACILITY WITHIN THE NEW ZEALAND CONTEXT

I have been advised about the above research and will be available throughout the project to support and advise both the researchers and participants on request.

The support of the local Kaumata group is also available.

Gala August

Maori Whanau Liason Officer

Te Omanga Hospice

APPENDIX VI

Letter to Ethics Committee

23rd January 2008
Jiska Van Bruggen
Central Ethics Committee Administrator
Ministry of Health
Wellington

Dear Jiska,

CEN/05/12/091

TO EVALUATE THE INTRODUCTION OF THE LIVERPOOL PATHWAY FOR THE TERMINALLY ILL/ DYING PHASE IN AN AGED CARE FACILITY WITHIN THE NEW ZEALAND CONTEXT

I am seeking approval from the Ethics committee, to extend the above research to further explore the experiences of caregivers who work with the dying in aged care facilities. The results of the focus group, stage three of the research, revealed powerful insights into the work of the caregiver. I would like to interview 3 to 5 caregivers individually, about the way they care for the dying, what they bring to the role through life experience, and what influence education has had on their work life. A consent to participate in further interviews would be obtained and presented to the ethics committee.

I am enrolled at Victoria University, and am completing my MA Applied (Nursing) this year. This extension of the research will be used as part of my master's degree.

Many thanks for your consideration.

Yours sincerely

Kate

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Palliative Care Nurse Specialist Educator
Te Omanga Hospice
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APPENDIX VII



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
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3 March 2008

**Ms Kate Gellatly
Te Omanga Hospice
136 Woburn Rd
Lower Hutt**

Dear Kate

CEN/05/12/091

To evaluate the introduction of the Liverpool Care Pathway for the terminally ill/dying phase in an aged care facility within the New Zealand context

Thank you for your letter received in this office on 26 January 2008. Your request for extension of your study has been approved by the Chairperson of the Central Regional Ethics Committee.

Ethical approval has been confirmed by the chairperson under delegated authority until the end of March 2008 and a final report will be due at this time.

If you have any further questions please feel free to contact me.

Yours sincerely

Jiska van Bruggen
Central Regional Ethics Committee Administrator

APPENDIX VIII

Information Sheet Phase Two

UNCHARTED WATERS - INFLUENCING PRACTICE THROUGH A LIFE COURSE APPROACH: How caregivers life experience can influence the care they give to the elderly at the end of life

The purpose of this study is to explore care givers experience in caring for people who are dying, what they bring to the role and what influence education has had on their work life.

You are invited to meet with the researcher to be interviewed for the above study. The interview will be a conversation between researcher and participant, focusing primarily on what changes you have made in your work life through education and what you bring to the workplace through your own life story.

Study Procedure:

This semi-structured interview will be audio taped and transcribed. The audiotapes and transcriptions will be locked away when not in use and a copy offered to you. The original will be kept for ten years. Your participation in the study will have no detrimental effect on your employment and you may withdraw at any time if you so wish. Anonymity of participants is assured in the research reports and publications.

This study will be conducted by Kate Gellatly, Palliative Care Nurse Specialist Educator, Te Omanga Hospice as part of a Thesis for the degree of Master of Arts (Applied) in Nursing at Victoria University, Wellington.

Consent and confidentiality:

Confidentiality of participants contributions in all drafts and in the final report is assured. At the completion of the study all research data will be destroyed.

If any issues arise, participants may contact the Principal Researcher, Kate Gellatly, PCNSE, at Te Omanga Hospice (Phone 566 4535).

APPENDIX IX

CONSENT TO PARTICIPATE IN THE STUDY PHASE TWO

UNCHARTED WATERS - INFLUENCING PRACTICE THROUGH A LIFE COURSE APPROACH: How caregivers life experience can influence the care they give to the elderly at the end of life

PRINCIPAL RESEARCHER/INTERVIEWER: Kate Gellatly, Palliative Care Nurse Specialist Educator, Te Omanga Hospice, Lower Hutt

TIME AND PLACE OF INTERVIEWS: Convenient to the participant.

PURPOSE OF THIS PROJECT:

The purpose of this study is to explore care givers experience in caring for people who are dying, what they bring to the role, and what influence education has had on their work life.

PARTICIPANTS COMMITMENT IN PARTICIPATING IN THE STUDY:

You are invited to meet with the researcher to be interviewed for the above study. The interview will be a conversation between researcher and participant, as to what changes have been made in your work life through education and what you bring to the workplace through your own life story.

This semi-structured interview will be audio taped and transcribed. The audiotapes and transcriptions will be locked away when not in use and a copy will be offered to you for your use. The original will be kept for ten years. Your participation in the study will have no detrimental effect on your employment and you may withdraw at any time if you so wish. Anonymity of participants is assured in the research reports and publications.

INFORMATION DISSEMINATION:

The research findings will be presented to:

- Ø Victoria University
- Ø Hospice NZ Conference
- Ø Gerontology Conference

(and other appropriate professional conferences or seminars)

Research findings may be offered for publication to:

- Ø *Nursing Praxis in New Zealand*
- Ø *The European Journal of Palliative Care*
- Ø *International Journal of Palliative Nursing*

(and other appropriate publications)

STATEMENT BY PARTICIPANT:

“I have read the information sheet and any questions have any been answered to my satisfaction. I understand that I may ask further questions at any time.”

“If I agree to participate and understand that I have the right to withdraw from the study at any time before analysis commenced”

“I agree to contribute to the interview on the understanding that my identity will be protected.”

I AGREE TO TAKE PART IN THIS STUDY

Name of Participant:

Signature:Date:

Name of researcher:

Signature:Date:

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