INTERTWINING THE ROLE OF PARTNER AND CAREGIVER

A phenomenological study of the experiences of four New Zealand rural women
who have cared for their terminally ill partners.

by

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ABSTRACT

The stories of the women who live and work in rural settings in New Zealand have begun to reveal unique contributions that they have made to their families and community. Meeting with and listening to rural women's stories reveals insights into the character of these powerful women.

This research study evolved from a trend the researcher observed as a district nurse providing community palliative care in rural New Zealand; that the majority of carers of those who are terminally ill in home-settings are in fact women.

This qualitative study aimed to explore through guided conversational interviews the experiences of four New Zealand women who have cared for their terminally ill partners who have subsequently died.

The study investigated if these women's experiences were comparable to that of other women in existing palliative care literature. This research project focused particularly on elucidating the women's experience of intertwining the role of partner and caregiver. Heidegger's hermeneutic philosophy informed the methodology because he focused on what it meant to 'be' rather than 'how we know what we know'. The project focused on the meanings the women made of this dual role in their lives. Women already in the role of partner were now faced with the added responsibility of caregiver to meet the complex needs of their loved one.

Usually they had no training to prepare them for this experience. The study reveals ways in which the visiting palliative care nurse becomes very important to them. The women's own voices reveal the high level of respect for their partners and address the harsh realities, revealing poignant and striking concerns in their lives. These stories are shared with the intent of enriching nurses' and other health professionals' understanding of the women's experiences.

The intention of the study is to highlight the need for closer attention by nurses to women's requirements when caring for their partner at home.

Understanding these women's experience is not only a way of honouring these remarkable women but more widely it will inform and possibly transform practice through guideline and policy refinement.

KEY WORDS: terminally ill, New Zealand, rural, women, partners, caregiver, home-setting

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KEY TO TRANSCRIPTIONS

<i>Lucida Handwriting</i>	Direct quotes from field journal
<i>Italics</i>	Direct quotes from practice diary
Century Gothic	Exemplars from the women interviewed
[...]	Words, phrases or sentences left out
()	Information added to clarify context or meaning
//	Pause present in original material

DEFINITIONS OF TERMS IN RELATION TO THIS RESEARCH

Rural: The area is defined as rural in that it has a population of less than 10,000 (Ministry of Health, 1999, p.38). In the 2001 census the area researched had a population of 4791. Of that, 1188 were in the township and the remaining 3603 were in the surrounding area. The area is geographically large. The nearest base hospital is 1.5 to 3 hours away depending where in the region the residents live. The area was not identified in the study.

Terminally Ill: This term is used to describe the person whose death is expected as a result of a natural outcome of a particular disease. These people and their carers are aware of the diagnosis and that no more curable treatment is offered. Generally people enter our service if their end of life is expected to occur in a year or less.

Data: This refers to all the narratives that were recorded at the time of the interviews and the subsequent transcribed text of these interviews. Data also refers to the information recorded in the journal I kept.

Tapes: Refers to audiotapes.

Participant: This term refers to the women who were interviewed. They did not assist in the interpretation of text but received a copy of the transcript of the interviews to check that it was factually correct.

Palliative Care: *The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms and of psychological, social and spiritual problems is paramount* (World Health Organization, 1990, p.11-12).

It is also understood that the goal of palliative care is the achievement of the best quality of life not just for the patient but also for families and whanau.

PROLOGUE

WOMEN'S WORK

Women tend the dying
Women mind the living
Women heed the calling

Women, notice the rhythm
that simple rhythm that exists in the living
that is also found in the dying

Women, listen to that gap
between the last breath and the eternal
a quietly still sanctuary

Women, touch cold cyanotic lips
kissed by anguished mouths
hot frenzied hands rub hard to bring forth
Warmth where death waits

Women, look at eyes
that once burned brightly becoming dim
eyes that can no longer see
turn within and finally understand

Women, gather and unite fragmented family
to catch the final fleeting moments
the fire of belonging becomes banked
in deep sorrow filled hearths
the gift of the present glowing softly
in the heart where once gurgling and gasping reigned

Women, carry high on heavily laden shoulders
the memories, the knowing
the magic that is in the stillness

Women tend the dying
Women mind the living
Women heed the calling.

Diane Johnson (2002)

CHAPTER 1

INTRODUCTION: WHY THIS TOPIC?

1.1 Researchers Interest

I work as a district nurse in a rural community. My field of interest is palliative care. In rural New Zealand the district nursing service does much of this work. In the geographical area where I work this is how the service is provided.

Since being involved in the care of people in their own homes, I have observed the ability of rural women to care for their terminally ill partners; they cope, make do, improvise, self-manage and just get on with the job.

At the end of days where I have visited a person who is dying I find it helpful to record moments in a journal. There is a certain pleasure in the writing down of events witnessed and special moments that deepen my interest in not only those dying but those who take on the care-giving role. In my journal I combine reflective writing and fiction. This love of writing helps refine the expertise in my practice and is an essential component of my practice reflection. The following excerpt is the first entry in my journal. I was so impressed with this woman I needed to write of my admiration for her:

What an amazing woman, today she came up with a novel way to wash (him) now he can no longer step over the bath for his shower. A paddling pool in the lounge- (him) on the shower stool in the paddling pool with buckets of warm water. (He) loved the feel of the water on his body and a bed bath didn't do it. (She) is truly amazing.

Whenever there is a problem (she) is able to improvise.

It is my view that in palliative care it is a common and important part of professional practice to write, reflect and represent points from people's stories, whilst protecting

their privacy. The intention being that practitioners reflect on their own practice when stories are presented as text. I believe by doing this we awaken sensitivity to the lives we all live as members of a community. This in turn allows us to make time to reflect on life. In research terms, stories invite the reader to have a deeper understanding of the participant's world of palliative care. Listening to stories, conversations and the mutuality of evolving assessment and responses to the situation is central to the way I practice. I was alert to this before the study. The interviews with the women in this research reinforced this position.

I have observed that there is a cost to care giving in terms of these women's own health and quality of life. More support and help is required for them to carry out this role and remain intact.

The diagnosis of a terminal illness, especially cancer usually comes as a shock and upsets normality. It is an area of nursing where just attending to the tasks of caring for a person who is very ill is not enough because it is recognised that the person will not survive their disease. My view is that as nurses we cannot stop the inevitable moment of death of a loved one, but I argue that we can help patients and families cope by providing services and care that meet their needs. When I am in discussion with a family, I present my position and role and together we evolve a plan for working together through whatever will unfold. It has been of particular interest to me that the majority of those involved in caring for the terminally ill person at home are women. This does not mean that the majority of people who are terminally ill in a rural setting are men; it does however, suggest that women are caregivers and partners for their terminally ill husbands in my locality.

I have lived and worked in this area for many years and have had the privilege of observing trends in practice and the community. My interest in shaping care in the community has evolved to the point where I recognised that through my own deepening understanding of just what is required to care for a dying person at home, I and women in the community could offer some insights into what occurs.

It is my observation that nurses reflect on situations they are involved in and often try to imagine themselves in the same situation. Some, like myself, record these reflections in journal form. Others discuss or debrief with colleagues about amazing and challenging situations. This thesis reveals some reflections taken from journal recordings. One such example is written below:

I think my overriding memory of the first visit and the preliminary observation made was what a tragedy this was for (her) even more than I thought for (him). I tried to image myself in that situation- (he) was only 5 years older than my husband.

These reflections have been carefully documented, as will be explained later, in a fictional form where necessary, to protect members of the community and colleagues.

Through my involvement with palliative care nursing I have learnt to appreciate my own family. It reinforces to me how lucky my family and I are to be healthy and well but how important it is not to take anything for granted; I think it is easy to believe tragedy or illness will never affect your own life.

I believe this reflection and the observations I have made in terms of women caring for their partners have highlighted the interest I have in researching the experiences of these women. I felt that if I could find a way to tap into their experience they could provide a great deal of information to assist nurses working in the community

and other women who take on the caregiver's role. While writing of their experiences for public readership would be difficult, my intention as a clinical nurse researcher was to document their conversations and then explore their experiences to see if they matched my own assumptions and to review their experiences against a range of documented research evidence. In particular, I explored the meanings they attributed specifically with regards to combining their role of partner and caregiver. This was of particular interest as I had only been able to locate limited research identifying this phenomenon internationally and I found no studies undertaken specifically on or identifying this topic in New Zealand.

1.2 Study Overview

This study examines the experiences of four New Zealand rural women who have cared for their terminally ill partner who has subsequently died. I proposed that an appropriate qualitative design for researching this sensitive topic was a conversational interview methodology that was informed by Heidegger's interpretive phenomenology.

The four women who agreed to take part in the study were interviewed using a framework for interviewing guided by researchers Colaizzi and Van Manen. The collected data was analysed initially using the first six steps of Colaizzi's (1978) framework for analysing interviews. This first level of analysis enabled me to gain a position from which to use the work of scholars Max van Manen and Patricia Benner to conduct a process that allowed me to deepen my understanding of women caring for their partners.

1.3 Outline of Chapters

Chapter one outlines my interest, concerns and focus in the topic being researched and provides an overview of the thesis. I introduce my interest in palliative care and my intrigue with rural women I have encountered when conversing with them and assisting them to care for their terminally ill partners. It also introduces some existing assumptions pre-understandings and my love of writing about what I witness, and reflect on.

Chapter two explores stories from practice and relevant literature that informs the research topic. A review of the literature is presented, focusing on dying at home, and the impact on the women who provide palliative care at home. The stories from my practice journal are used to identify my philosophy of practice and my existing assumptions and possible biases. The final section of chapter two introduces the reader to the research focus, an exploration of the lived experience of a female partner caring for her terminally ill partner.

In chapter three I discuss in depth the research methodology, exploring Husserl and Heidegger's perspectives of phenomenology and debate the value of using Heideggerian phenomenology for this study. I also examine my own philosophical framework as a clinical nurse researcher and the use of phenomenology in nursing research.

Chapter four specifies the design of the study. It outlines the setting, participants, methods used for gathering the data and how rigour and trustworthiness will be hallmarks used to validate the findings. The process for conducting the analysis and

interpretation of the data is described. The reader is introduced to my appreciation of the scholarship of Colaizzi, van Manen and Benner and their influence on nursing research is considered.

Chapter five is a detailed summary of the numerous ethical issues that needed to be addressed in conducting this project which included addressing the research and practice implications of the Treaty of Waitangi, one of the founding documents in New Zealand.

Analysis and interpretation of the conversations with the four women participants and my reflections is the focus of chapters six and seven. Chapter six introduces the reader to the four women in the study. The chapter explores my own pre-study assumptions, understandings and biases and supports these with pre-existing literature and direct quotes from the interviews with the participants. The two themes elicited from the conversation transcripts of responses to health issues and inner strength are explored.

Chapter seven examines and interprets the understandings and meanings the four women revealed when they were both partner and carer for their dying husbands.

Discussion of the findings and implications for practice, the role of the palliative care nurse, and the limitations and strengths of the study are revealed in chapter eight.

Chapter nine synthesises the ideas presented in the thesis and identifies and offers some directions for practice education, policy and research. The final words belong

to the women. This chapter briefly summarises the key points identified by the women, these remarkable women who turned their full attention to being both partner and carer for their terminally ill husbands.

CHAPTER 2

WHAT IS ALREADY KNOWN?

Chapter two explores whether dying at home rather than in an institutional environment is an increasing option and identifies possible reasons for this. It examines if women are in fact the main providers of care in a home-setting and the impact of this on their lives. Stories from practice highlight my own assumptions of this practice, and a literature review of these areas reveals evidence of current practices and trends in thinking.

2.1 Dying at home

The New Zealand Palliative Care Strategy states, “In New Zealand, palliative care is mainly delivered to people in the home” (New Zealand Palliative Care Strategy [NZPCS] 2001, p.34). It is obvious in my practice environment “People who live in rural areas may often have significantly reduced access to palliative care” (NZPCS, 2001, p.45).

The Ministry of Health (2002), in New Zealand predicts that there will be an increase in cancer over the next decade, for both genders and in most age groups. Of those diagnosed, approximately 50% will die from it.

Through my involvement in caring for dying people it is also clear to me that most people express a desire to die at home. There are however issues associated with this desire to die at home, which are recognised in national policy. “Patients who do not have sufficient support at home may have to be admitted to a hospital, hospice or rest home” (NZPCS, 2001, p.44).

The funding issues are complex and multifaceted no matter the place of care and are beyond the scope of this study. However with hospice services in New Zealand relying greatly on fundraising and donations, possible links between patterns of care and styles of funding would make an important future study.

International research supports the view that people wish to die at home for a particular stated reason and this is generally framed as follows: In an editorial written for the Clinical Geriatrics Journal (1999), the opening line states “ Most terminally ill patients embrace a desire to die at home rather than in a desolate and sterile institutional environment ”(p.1). I would argue that it is not so much that the dying person doesn’t want to be in an institution, as they fear being away from that which is familiar. I recognised that to hand over control, change routines and experience separation from the support of friends and family must be very frightening.

I am also aware that palliative care does not exclusively offer care for people with cancer, but cancer sufferers constitute by far the largest portion of those receiving palliative care services, both as inpatients and in a home-setting. Those who do not have cancer might include a person with motor neurone disease or a person who has been discharged from an acute service such as dialysis or intensive care for terminal care at home. I totally support the person’s decision to be in their own environment and can see from a hospice service point of view this is also most desirable. While I do not have figures for New Zealand it could be said that the cost savings might be considered to fall in the vicinity of what has been calculated in a North American setting, where cost savings of 39% to 51% have been made for a hospice service, when terminally ill patients are nursed in a home hospice service rather than in institutional hospice care (Carney & Burns, 1991). In a cost contained environment,

according to the above argument, a hospice service interested in saving money may well put pressure on families to care for their loved ones at home whether they are prepared and supported to undertake this or not. American nurse researchers Boland and Sims (1996), noted in their grounded theory research that there had been a tremendous growth in the number of patients being cared for at home. They argued that one of the main reasons was the pressure to contain health costs. With this pressure, the need to support the carers is highlighted. Boland and Sims acknowledged this when they said,

As home-health care and the pressure to reduce health cost increases nurses should support those who care for people at home. High quality care must extend far beyond the boundaries of hospitals into the lives and experiences of caregivers at home. (Boland & Sims, 1996, p.58)

This assertion resonates with my own view on the important role that nurses have in home care. While I have not experienced any coercion to care for people at home in New Zealand due to cost containment, it interested me that in the very different rural setting of Uganda, another study by Taylor, Seeley and Kajura, (1996) echoed the findings of the above study.

In my practice area, as far as I am aware, there has been no pressure from health services to care for terminally ill people at home. However I believe there is a social and cultural expectation that this will happen. There may be a need for future research to see if in fact we have missed a cue in the community that an economic imperative does in fact drive the increased numbers of people dying at home. If the trend is those dying wish to remain at home then it is crucial that the experiences of those providing the care needs to be examined. How else will services know if what they are providing is appropriate and adequate? And how will nurses know if they are able to sustain the need for care of the terminally ill at home, the cost of which is

also uncalculated in New Zealand. The training for this as a specialised role is acknowledged as needing postgraduate education in the UK(Calman-Hine Report, 2004) and is supported by the Clinical Training Agency Funding for the Postgraduate Certificate in Palliative Care Nursing in New Zealand.

2.2 Women as providers of care in a home-setting

I talked with (her) about the possibility of (him) dying soon. Was she comfortable with the idea of continuing to care for (him) at home? (She) told me she was his wife and was happy to be able to care for (him) at home and said the decision was made easier knowing there was support from her family, GP and hospice service.

When I reviewed the international literature centred on home-based care it demonstrated that in the home-setting the majority of carers are women. In the USA a nurse researcher found, “It is not unusual for wives to act in a caregiver role. In fact, women are socialized to make personal sacrifices and care for their families” (Schott-Baer, 1993, p.234-235). The following Canadian research further supports this:

It is estimated that 72% of family caregivers are women (Gaynor, 1990). For male patients who are married, responsibility for the care tends to fall on their wives. This is a 24-hours-a day responsibility, which may continue for years. (Ross & Graydon, 1997, p.24)

This implies that the challenge of care falls on women when their partners are dying. This can be unexpected and there is no known time frame for what is to be encountered. The following reveals the personal sacrifice made by the woman in this reflection:

As we talked today (she) told me how difficult it was caring for him. He refused to talk about how ill he was. They had not been together long and this was not in the plan. The relationship had its ups and downs and things did not always run smoothly at the best of times. (He) being ill had added another tension and strain that had made things worse. But (she) felt she could not leave now.

The American study by Boland and Sims (1996), around the experience of caregiving for ill family members found that of the 17 caregivers interviewed, 14 were women. These women were caring for varying age groups and the medical problems related to a variety of illnesses, including birth defects, cancer, diabetes, strokes and surgery recovery. Another study carried out in Canada, by Weitzner and McMillan (1999), looked at quality of life issues for family caregivers of people receiving home hospice care. Of the 238 caregivers involved in the study 75% were women. It was not surprising to find all 9 carers in a study carried out in Scotland by Gall, Atkinson, Elliot and Johansen (2001) around supporting carers of people diagnosed with schizophrenia, were women. If we assume therefore that it is possible, although not soundly documented as yet, that the majority of home based carers are women, then we can consider the possibility that the majority of support for home based palliative care, for terminally ill men is provided by their female partners. In future it would be interesting to research the literature to ascertain the role of other family members. "According to Emlett (1996) it can be assumed that the supportive person for critically ill men is usually the wife..." (cited in Bergs, 2001, p.613). Identifying New Zealand literature specifically identifying women caring for their terminally ill partners proved difficult. However one notable study by Niven (2001),

a phenomenological thesis entitled, *Living toward Death*, also noted the need for further study on kin as caregivers. “As the chronicity of cancer increases, the issue of the effect on kin as caregiver will need further study”(Niven, 2001,p.76).

2.3 The impact of being a carer at end-of-life: stories from practice that highlight the researchers’ assumptions and pre-understandings

Interestingly van Manen’s suggestion that it is not that the researcher knows too little about the phenomenon being investigated but that they know too much (1984), and perhaps do not take the time to reveal what they know, has provoked me to be courageous and reveal what my reflections are on this topic. I have been involved with women who care for their dying partners for a long time during my nursing career. And therefore it is difficult not to already have assumptions, beliefs and biases. I argue that it is important to bring these to the research at an early stage, as they are part of the study. I have therefore highlighted these understandings in direct quotes from my practice journal, which is the diary I write in often after my working day. This diary is not to be confused with the field journal discussed in Chapter 4 and used as part of the interview process. I have incorporated fictionalised versions of these reflections [as above] from this journal and interspersed this with research evidence to show how when searching for literature in this area stories from practice came to mind. Each reference and story provoked insights from me, enabling a narrative to evolve. This allowed me as a nurse researcher to conceive of the women, their partners and families in this situation.

An Australian article by Aranda and Hayman-White (2001) reported that in a phenomenological study of 42 family caregivers involved in home-based palliative care, the family caregivers are involved in symptom management, therapeutic interventions and take on almost total responsibility for household tasks.

I recalled a couple where:

(He) was in bed today. (She) had obviously been crying and continued with the vacuuming while I talked with (him) in the bedroom. The smell from the kitchen suggested that the evening meal had already been prepared. (She) walked out to the car with me and confided that she was concerned about (him). (She) told me (he) was not taking his medication regularly or correctly even though (he) was telling me he was. (She) and I talked about this. (She) is frightened to interfere in case he gets angry. I said I would talk with him and encourage (him) to allow (her) to have a more active role in helping him with his medication.

As reported by North American researchers Navaie-Waliser, Feldman, Gould, Levine, Kuerbis and Donelan (2002), reliance on family caregivers without considering their ability to provide that support can create a stressful and potentially unsafe environment for the caregiver and the receiver of the care.

This situation was particularly obvious in this family setting:

This morning started earlier than usual. A call out at 0630hrs. (She) was clearly distressed as (he) was extremely short of breath. (She) did not seem to realise it would be easier for him to get his breath if he was sitting upright instead of lying flat in the bed. We were able to prop (him) up on some pillows, (she) could not have done this on her own, it was difficult enough with the two of us. Once he was more relaxed his breathing eased. How does (she) manage day after day? It must be difficult for older women who are frail themselves to help

their husbands who are physically demanding and dependant on their wives for much of their care. (she is already suffering from a sore shoulder helping him out of a chair).

Maybe there is an implicit assumption that female partners should and are able to cope with caring for their terminally ill partners? Perhaps we have an expectation that women involved in caring for their terminally ill partner should provide support and take part in interventions that they are ill prepared to provide?

This reflection reveals needs and wants as becoming a balancing act:

(She) appeared at breaking point today "No one thinks about me, family members arrive and just sit."

(He) expressed his frustration with friends visiting stating that he and (she) had no time to themselves. It must be a bit of a balancing act as (he) obviously likes to see some of the visitors but the time they have left together is important and they resent the intrusion on that time.

(She) said it is hard to get information, "they" (meaning the doctors) never tell you much.

(She) said the nurses are always busy and I don't like to hold them up.

Bergs (2001) phenomenological study highlighted that wives neglect their own health and she uncovered health problems that these wives experienced. Problems identified were physical fatigue, sleeping difficulties, frail mental health and feelings of depression. Gaynor (1990) a North American researcher, also noted sleep deprivation, depression and stress-related disorders, specifically hypertension and heart disease, were common among female caregivers.

I recall many situations when the caregiver was, in my assessment, simply worn out as this reflection reveals:

The relief seemed only temporary and (he) became more and more confused and disorientated. (She) was finding it extremely difficult to manage. (She) admitted to being very tired and a recent BP check highlighted the need for medication for hypertension. We chatted about some time out. (He) was admitted for respite/symptom control. Although (she) was reluctant to be separated from (him) for any length of time (she) caught up on some much needed sleep. After a few days (he) returned home again.

These same problems were noted by American nurses, Munro and Sexton (1985), when they collected data from questionnaires to determine the impact of a husband's chronic illness on the spouse's life.

It appears as a consequence of the stress that lifestyle changes occur for the wife who cares for her husband. A Canadian study carried out by Ross and Graydon (1997), very usefully reported these changes in the actual phrases used by those studied. Phrases such as *being housebound, decreased visitors, I have to do everything* and *I miss the help around the house* indicate the state of being. From comments like this we can assume that due to terminal illness, the partner is no longer able to participate in the activities and chores they usually do thereby increasing the burden on their female partner. Not only do they become the main carer, they are now responsible for all the running of the household. It appears the demands placed on these women are extensive.

It seems obvious that the work falls on one person but when it is written as a reflection it becomes quite stark:

Not only does (she) attend to all his caring needs but today when I called (she) was out mowing the lawns.

(She) expressed concerns about not feeling she can leave (him) for any length of time. (She) is finding it difficult to do the shopping and pay the bills.

(She) said the biggest problem is that she doesn't drive and she hates relying on family to take her shopping etc. (She) doesn't like imposing on their time.

Such evidence supports my contention that women are the main carers and that female partners of those who are terminally ill provide the majority of care in a home-based setting. I concluded that further research in a rural New Zealand setting would usefully identify issues and generate knowledge pertinent to the New Zealand situation. Given the statistical projections for cancer, which indicated increases and the community desire to die at home, home-based care looks likely to increase.

Nurses are the ideal researchers to examine the concerns and issues raised by female partners as carers to help support them in this role. By enriching our understanding of these women's experiences I believe we will be better able to provide this support and develop appropriate specialised palliative care services in rural settings.

2.4 The Question: the research focus

I framed the research focus as a exploration of the lived experience of a female partner caring for her terminally ill partner because the longer I work in the field of home-based care, the more I observe rural women providing excellent care for their terminally ill partner.

In my work role I form a working partnership with these women and rely on them as integral to the holistic assessment I carry out at each visit. They are able to provide up to date information about their partner and I have become genuinely interested in hearing about their experiences. It is the documentation of these experiences, the everyday conversations and often taken-for-granted, that inform this study. Perhaps the key to conducting this research was the recognition that these women could be an important source of detailed knowledge for rural nurses and other rural women in the same situation.

The objective of this research was therefore to examine the experiences of 4 rural women in New Zealand who have cared for their terminally ill partners, thereby gaining their perspective of the lived experience of this phenomenon. To understand their perspective I needed to document their stories and reveal the meanings these women made of this unique experience and discover if the assumptions and pre-understandings I already held, matched what I found when I interviewed the women. It also required that I examine their experiences in terms of the existing research evidence documenting the intertwining role of partner and caregiver. Focusing on the women's own words of our conversations, drawing the women out about their ability to assess the situation guided my direction of the study. Reconsidering and valuing my ability to sensitively engage the women and then interpret their stories and

present them as exemplars that they both recognised and supported was essential to the process.

Having listened to these conversations I asked women who had cared for their terminally ill partner to tell me most specifically about their experiences of intertwining the role of partner and carer. I felt there was a necessity to have some questions to use as prompts during the interview. These will be discussed under the section pertaining to method.

In this chapter I identified the focus, aims and specific objectives of the study. I identified there is a need for the study due to the increase in people dying at home and possible reasons for this. It also discussed women as caregivers and the impact of this when involved in end-of-life care. An important area covered in this chapter was to acknowledge my assumptions and pre-understandings of this phenomenon. I used fictionalised stories from my own practice to illustrate issues exposed in existing research on this topic.

The following chapter will examine phenomenology, the methodology chosen to undertake this study.

CHAPTER 3.

AN APPROACH TO RESEARCH: PHENOMENOLOGY

3.1 Introduction

Since beginning academic study I have been more and more drawn to the philosophy of phenomenology and what it has to offer nursing in terms of practice, research and knowledge. I was interested in using interpretive phenomenology to explore the experiences of rural women caring for their terminally ill partners. In this chapter I briefly explore the history of the phenomenology movement begun by Edmund Husserl (1859-1938) and look at three of the central concepts in his perspective, lifeworld, intersubjectivity and intentionality. Secondly I examine the phenomenological perspectives of Heidegger in relation to nursing research discussing the major features of his approach. Thirdly I look at recognising the importance of my own philosophy in undertaking this phenomenological research. The fourth area addressed in this chapter is the use of phenomenology in nursing and I introduce the reader to Patricia Benner, a well-known nurse phenomenologist. The chapter concludes with a summary of phenomenology and justification of my use of this methodology.

3.2 Phenomenology: An exploration of Husserl's perspective.

Phenomenology is a 20th century philosophical movement developed by Husserl (1859-1938). The movement is dedicated to describing the structures of experience as they present themselves to consciousness, without recourse to theory, deduction or assumptions from other disciplines such as the natural sciences (Microsoft ® Encarta ® 97).

According to Gillis and Jackson (2002) Husserl introduced two ideas that are pivotal in phenomenology: lifeworld, the world of the lived experience and intersubjectivity, what we experience in our daily lives and our understanding of these experiences. In our lifeworld we are able to experience subjectivity, our own thinking, feelings and our personal feelings. We know that lifeworld is central to phenomenology and that lifeworld is our own experience. Husserl expanded on this. According to Drew (1999), Husserl understood that it is possible for all of us to have the capacity for self-awareness and that we are aware of each other's capacity do this. This reflective ability allows us to "continually expand understanding of the world and our relationship with it and with each other"(Drew, cited in Polifroni & Welch, 1999,p.263). This major concept, of intersubjectivity, places great importance on subjectivity. Our thoughts and feelings enable us to create our truths and realities and what we discover and know appears in our consciousness. They appear in our consciousness, as we understand them, without influence from theory or others. This is our experience of the lifeworld and I believe it has as much truth and validity as any other view:

If I, as a human being employing my natural modes of thought, look at the perception, which I am undergoing at the moment, then I immediately and almost inevitably apperceive it (that is a fact) in relation to my ego. It stands there as a mental process of this mentally living person, as his state, his act; the sensory content stands there as what is given or sensed, as that of which I am conscious; and it integrates itself with the perception of objective time. (Husserl (1964), cited in Polifroni & Welch, 1999, p.247)

Another central concept of Husserl's phenomenology is intentionality " the specifically phenomenological act of the mind by which the ESSENCE of a mental phenomenon is constituted" (Bullock & Trombley, 1999, p.435). ESSENCE is defined as "The set of properties of a thing or of instances of a kind of thing which that thing or those instances must possess if it is to be that particular thing or they are

to be instances of that particular kind” (Bullock & Trombley, 1999, p.283). Drew (1999) noted that these ESSENCES are then universal patterns of experiencing. Husserl made intentionality the founding characteristic of phenomenological reflection. Through a series of reductions he hoped to reach the objective truth. One of the most important reductions for Husserl was that of bracketing, a process by the researcher in which they put aside their own views and perceptions around the topic with a view to not influencing the research material.

If using Husserl’s method of phenomenology in research, using his beliefs around lifeworld and intersubjectivity, the researcher undertakes repeated reviews of the data to find the ESSENCE, themes or what stands out. “It is this ‘standing out’ that phenomenological researchers then must consider, for it signifies the intentionality that Husserl repeatedly emphasized as central to phenomenology”. (Drew as cited in Polifroni & Welch, 1999,p.269). Husserl concentrated on the epistemological concerns of what kind of knowledge was possible and how that knowledge would be both adequate and valid. Welch (1999) noted that a criticism of Husserl was that while he described a method of research he never used it with humans.

3.3 Heideggerian Phenomenology.

Martin Heidegger (1889-1976) was a student of Husserl. He expanded on Husserl’s epistemological stance of how we know what we know and changed the central focus of philosophy from epistemology to ontology. The central question for him became what it means to be, rather than how we know what we know (Welch, 1999). He investigated the nature of existence of that entity which, I am – he called it Dasein. Dasein is a particular way of existing, literally Being- There. While it is a difficult concept to grasp, it is essential to understand when using his perspective in nursing research. Dasein then is not just about physically being in the world; it is

also about the way we are in the world, Being-in-the-world. Being-in-the-world allows us to see what is significant and that significance is the background for more reflective understanding (Welch, 1999). If we are able to understand a patient/family in a context of illness, for example, what they value or find significant shows up. It is also important to note that 'world' in a phenomenological sense is not the physical world. "Phenomenologically, world is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture"(Leonard, 1989, p.42). We depend on our shared history, skills and practices to give us meaning and intelligibility (Leonard, 1989). We are able to share these background practices and familiarity. This makes it possible to have shared and individual interpretations of the world (Plager, 1994). Because we are so familiar with our world it allows us "to make sense of what we are doing, makes it possible to do the activities we are doing, and allows for possibilities we have not yet done"(Plager, cited in Benner, 1994, p.70). Plager, noted that the downside to this familiarity is the possibility of certain aspects being missed because many things are taken for granted. For example it is possible to take good health for granted not considering what this means until we become unwell. It is evident that both Husserl and Heidegger were interested in what we know from experiencing it in our daily lives. However it is my view that what Heidegger believed was of more importance, was what that experience meant and to then interpret and analyse that information.

While Husserl argued that it was necessary to 'bracket' the interpreter's personal experience so as not to influence the research material, Heidegger did not agree. In Heidegger's hermeneutic or interpretive phenomenology, bracketing is not possible. Because interpretive phenomenology involves considerable reflection, it is impossible and indeed unwise to 'bracket' your own experiences and views of the

phenomena you are researching. Therefore, the interpreter and the interpreted cannot exist without each other. According to Drew (1999) hermeneutical researchers such as Heidegger believe that it is impossible to remain neutral because it is impossible to free one's self from being a member of the lifeworld, the foundation from which all research comes. It is however necessary to acknowledge our familiarity and background with a situation that allow us to interpret that situation. It is because of our background in a situation that we have a view. For example, my interest is in the experiences of wives caring for their terminally ill husbands. Because I am involved with this phenomenon I had many expectations, assumptions and pre-understandings of what might be revealed during the interviews. According to Gillis and Jackson (2001) these self-understandings must be identified and acknowledged as they could influence the interpreting of the text. It is however unrealistic to set them aside.

Heidegger's idea was to start with the kind of being that each of us manifests, in order to open up the more general question, and to adapt Husserl's phenomenology as a method to be used in the inquiry.
(Mautner, 1999,p.242)

According to Plager (1994,pg 122) the crucial issues in how a research project is approached are the questions that are asked and the researcher's self-understanding of the topic. She further believed that this was the claim made by Heidegger when he investigated the meaning of 'Being' in his book, Being and Time. In this study I have relied on other people's interpretation of his text due to time restraints and the obscure language he uses.

In summary, it appears that Husserl used phenomenology as an epistemological method to disclose what type of knowledge is possible to elicit. For Heidegger, whose philosophical stance was also grounded in phenomenology, he situated his

investigation with ontological concerns. He used hermeneutic phenomenology to discover what an experience or phenomenon meant for the person being investigated by interpreting and analysing the information collected. This form of human science offers a nursing research methodology that I feel is well suited to examine the experiences of nurses, patients and families involved in palliative care.

3.4 Personal philosophic framework.

I believe the tenets described in phenomenology could be seen as underpinning the nursing framework that shapes my practice. I see them reflected in the text of my own nursing philosophy that follows:

I BELIEVE NURSING IS A SPECIALISED
EXPRESSION OF CARING. THAT CARING ENABLES
ME TO FEEL CONCERN, TO FEEL A LOVE, OR
LIKING FOR MY PATIENT. IT IS HOW I AM ABLE
TO ATTEND TO, PROVIDE FOR AND CONNECT
WITH THAT PERSON.

THAT CONNECTION ENABLES ME TO GET TO
KNOW THE PERSON, AND TO TRY TO
UNDERSTAND THEIR WORLD. IT ENABLES ME TO
CARE IN A HOLISTIC WAY, CARING FOR THE
WHOLE PERSON NOT SEPARATING THE MIND
AND THE BODY, FOCUSING ON THE PERSON NOT
THE PROBLEM.

I BELIEVE IN THE PATIENT AND FAMILY BEING
INVOLVED IN ALL DECISIONS ABOUT CARE AND
TREATMENT OPTIONS, RESPECTING THEIR
VIEWS AND CHOICES, BEING SUPPORTIVE BUT
NOT INTRUSIVE, ACCEPTING THAT MY VIEW IS
ONLY ONE VIEW. I BELIEVE THAT IN ORDER FOR
ME TO PRACTISE EFFECTIVELY I HAVE TO
INTEGRATE MY PERSONAL AND PROFESSIONAL
SELF.

I also recognise that when conducting nursing research this philosophy supports the authenticity of the work when the chosen methodology bears some relationship to the researcher's own worldview and philosophy. It is necessary to have a deep interest in what it is you are investigating for it to be meaningful to the researcher and the readers of the study.

Drew (1999) noted that thoughtful reflection of our own experiences around the phenomenon being studied is required to understand why something is meaningful.

In doing this, our values and beliefs around the topic are closely examined.

When we understand our personal connection to a theme then we begin to look at our own consciousness of the phenomenon under investigation, and we have begun the interpretive process. If we simply describe a phenomenon, however succinct and exquisite the description, we have not given a phenomenological account of it. It is not enough to write about our participants' experiencing; our own experiencing of the study belongs to the data as well. (Drew, cited in Polifroni & Welch, 1999, p.270)

I have worked in palliative care for a number of years and much of the focus of my work is around being with the person who is dying. Aligning my practice around phenomenology has made me more aware of looking at the patient as a person and the necessity to be with the patient who is in need.

3.5 The use of phenomenology in nursing.

Since commencing my academic study I am aware that many nurses have and are exploring phenomenology to describe and understand nursing situations. Madjar and Walton (1999), suggest that the current interest in phenomenology "has something to do with what it is that nurses 'already know' about nursing" (p.2). They also suggest that,

Phenomenology offers nurses a way of thinking about their practice that is at once simple and familiar, and yet which brings forth understandings that are often novel and complex. The understandings made possible through phenomenological inquiry help to put meaning

into the everyday world of practice and human interaction. Given that nursing is concerned with some of the most intimate occasions in human life, it does not seem surprising that phenomenology, which allows nurses to reflect meaning of their work, should be attractive to clinicians and researchers alike. It offers a way to the soul of nursing. (Madjar & Walton, 1999, p.3)

This sits well with me and sums up nicely what attracted me to use phenomenology in this study. I believe that as a clinician my practice could be positioned within a framework that recognises the hallmarks of phenomenology.

One of the more well-known nurse phenomenologist is Patricia Benner. She has used phenomenology to examine the 'lived-world' of the patient/client. Benner used a phenomenological approach to understand and explain the lived experience of health and illness and what phenomenology has to offer nursing science and nursing practice. This can be seen in her work *Novice to Expert* (1984), *The Primacy of Caring* (1989) and *Interpretive Phenomenology* (1994). The phenomenological stance of Martin Heidegger appears to have greatly influenced her work and through Benner's scholarly inquiry I have found a desire to understand more about the experience of illness and suffering in the field of palliative care. I agree with Benner when she says, "Heideggerian phenomenology generates forms of explanation and prediction that offer understanding and choice, rather than manipulation and control"(Benner, 1985, p.10).

According to Gillis and Jackson (2002) phenomenologists validate knowledge that is derived from experience. They also believe that intuition is important in knowledge development and that intuition is developed through looking and listening. I argue this is certainly the case in expert nursing and the following exemplar from my journal demonstrates the importance of intuitive knowledge:

Today (his) catheter was not draining well and the urine was leaking around the catheter. (She) was having to change the clothes and

bedding often to keep him dry. This was an added stress and one (she) could do without. I had seen this happen before - particularly when someone is constipated. On questioning they did not think (he) was constipated as he had been on the toilet regularly and his bowels had moved. My intuition told me to see if (he) would allow me to check his rectum. (He) was obviously constipated and I needed to give him an enema to clear the backlog. This done the catheter flowed freely.

Nursing knowledge needs to be gained from a variety of research methods because the knowledge required in the science and art of caring is complex and challenging. For many years much of nursing knowledge was gained from the empiricist view. Polifroni and Welch (1999) noted that knowledge gained primarily through the old empiricist view appears limited/ lacking. It tends to generalise, be restricted to observation and have limited explanatory power. I argue it has a narrow view and is unable to see and present the whole picture or wider view. I believe an empirical perspective can result in paternalistic power relations. This was how the medical and nursing worlds were played out when nursing training was framed almost entirely on the medical model.

With nursing now gathering knowledge from nursing research it is clear that the exclusivity of the traditional scientific approach is being challenged. Nursing is more than a science and there is a need for philosophical examinations of nursing. I believe that with the number of studies undertaken by nursing academics using phenomenology as a methodology, nursing is joining the search for the fundamental issues of meaning. Studies such as Berg's (2001) phenomenological study of the experiences of women caring for their husbands with a chronic illness or Rose's

(1990) study on the inner strength of women, are examples of researching the lived-experience. By accessing these women's explanations of the phenomena they experienced in their daily lives and entering into that experience, useful data was generated and interpreted to add to knowledge around the concept of quality of life for wives who are caregivers and highlighted their meanings of these phenomena.

3.6 Summary

Wilke (1997) noted that qualitative research is often the best approach when researching aspects in palliative care. With my interest in listening to stories of the experiences of wives caring for their terminally ill partners, Heidegger's sensitive method of uncovering descriptions of this phenomenon appears to me to be an ideal choice. I believe like Heidegger, that it is not possible to separate oneself from the world and that our own involvement with others is what shapes our understanding and interpretation. Plager (1999) noted that reliance only on the Cartesian mode of inquiry leaves out significant meanings and that people's stories can fill considerable gaps in our understanding that the traditional empirical method does not include.

I have noted in my philosophy I believe that patients should be involved in all decisions about their care. In palliative care the focus is not just on the patient but includes care and involvement of the family. What better way to include families than by involving them in research? I hoped that the women in the study would establish some common ground around their experiences that can be used for further practice development.

Qualitative approaches are particularly valuable for understanding meanings of social events and practices. The reason for this is that it involves human science and is the appropriate method of research for sensitive topics and issues associated with death and dying. Heidegger's interpretive phenomenological approach is the

methodology I chose to research the topic. The phenomenological paradigm is less concerned with the issue of control and I agree with Benner (1985) when she says, "Heideggerian phenomenology generates forms of explanation and prediction that offer understanding and choice, rather than manipulation and control" (p.10). I believe that phenomenology underpins the nursing framework that shapes my practice and reflects my own nursing philosophy. Heidegger's philosophical stance was also grounded in phenomenology; he situated his investigation with ontological concerns. It is helpful if the selected methodology lines up with the researcher's nursing philosophy. This is because it is necessary to have a deep interest in what is being investigated for the study to be meaningful. Drew (1999) noted that thoughtful reflection of our own experiences around the phenomenon being studied is required to understand why something is meaningful. In doing this, our values and beliefs around a topic are examined. Heidegger was interested in what we know from experiencing it in our daily lives but of more importance to him was being able to interpret and analyse the information from that experience. Because interpretive phenomenology involves considerable reflection, it is impossible and indeed unwise to 'bracket' (your) own experiences and views of the phenomenon (you) are researching. Therefore the interpreter and the interpreted cannot exist without each other. Because we all have different realities, interpretive phenomenology is the research methodology best suited to hearing all voices. According to Drew (1999), hermeneutical researchers, such as Heidegger, believe that it is impossible to remain neutral because it is impossible to free one's self from being a member of the *lifeworld*, the foundation from which all research comes. It is however necessary to acknowledge our familiarity and background with a situation that allow us to interpret that situation. This resonates well with my own view; it is because of our

background that we have a view. Working with women who care for their terminally ill partners and having a deep interest in this phenomenon, I believe this form of human science offers a methodology well suited to examine the experiences of these women. It is for these reasons I have chosen a qualitative, hermeneutic or interpretive phenomenological methodology, informed by Heidegger, to research my topic.

This chapter has covered my interest in phenomenology and why it was an appropriate methodology to use for this type of research. I explained why I chose Heideggerian phenomenology and looked at how phenomenology influences my own nursing practice. It is in this chapter that I introduced Patricia Benner and the use of phenomenology in nursing today. As some researchers believe that qualitative research is limited I ended the chapter summarising my reasons for choosing a qualitative, hermeneutic phenomenological methodology, informed by Heidegger to research my topic.

The following chapter describes the design of the research project and it is divided into the areas covering geographic setting, the participants, methods chosen and my appreciation of the qualities in research such as rigour and trustworthiness. I discuss the steps I used in analysing the data from the conversations with the women and introduce Colaizzi and van Manen's role in the research. The chapter ends with discussion on how Benner and van Manen influenced thinking and writing about the women's experience in this study.

CHAPTER 4

DESIGN

4.1 Introduction

The following chapter outlines the design of the study. It describes how the women who took part in the research were eligible for inclusion and where the interviews took place. The methods used are detailed to describe the style for the interview process. A rationale is offered for the use and style of recording notes in a field journal. The contribution of qualitative research is higher when established criteria of rigour and trustworthiness are addressed in the search for research validity. The design outline includes a description of how the analysis of the data was conducted using Colaizzi's (1978) method as a framework. A significant aspect in this chapter focuses on the writing of the research. The reader will see now why I have identified van Manen and Benner as my guides in the writing of this piece of work.

4.2 Setting

The research was conducted in a New Zealand rural community setting. To ensure privacy of the participants the area has not been identified, although I realise it would not be difficult for the reader to find out where the research took place if they so desired. The actual interview was carried out in each of the respective women's homes. I felt the home is a natural setting that is private, comfortable and non-clinical. It is also possible that more in-depth information was gathered because it was the place where the experience occurred. I was able to arrange an optional place where the woman would also feel comfortable if the home setting was not suitable for her. None of the women took up this option.

4.3 Participants.

“Experience with the investigated topic and articulateness suffice as criteria for selecting subjects” (Colaizzi, 1978, p.58).

In this study the participants will be referred to collectively as the women. The women for this study were selected if they met Colaizzi's (1978) criteria of being able to acknowledge that they had lived the experience of the phenomenon of caring for their terminally ill partner. They needed to be able to articulate their experience as they had lived it in their daily life, to be eligible for participation. All four women recruited for the study were from a rural area and all four had experienced the role of being a partner and carer for their terminally ill partner. They had all experienced the death of their partner. Initially I suggested that the participants speak English, as I am unable to communicate in any other language. I also believed that if the women needed an interpreter it would detract from the communication that was essential in this study. The Ethics Committee advised that any of the potential four participants should not be discounted from participating if they needed an interpreter. Fortunately this issue did not arise. I set no age range for the participants being respondents as I consider age is irrelevant to the woman who has experienced the phenomenon of caring for her terminally ill partner. I decided to recruit women whose experiences were no more than 6 years old but no less recent than 1 year. Restricting the time frame allowed for the experiences to be fresh enough to be remembered well, but not so recent as to cause undue sadness. I acknowledged that the research could raise issues that were distressing. This concern is addressed in greater detail in chapter 5 in the section entitled Ethical Considerations.

The Ethics Committee required that letters (Appendix A) were sent out on a rolling basis, taking the first four who qualified rather than the first who responded to an

invitation to participate and then having to advise them that some potential participants might not be needed. Four letters were sent out and three women responded. After a period of two weeks a fifth letter was sent and the fourth woman responded. Four participants had now accepted the invitation to participate and no further letters were sent. I knew all four women recruited in the study in that I have been involved with them in my role as a palliative care nurse. While the number of participants was small, the rigour of the research is expressed in the richness of the in-depth material that the women revealed.

4.4 Methods.

4.4.1 Semi-structured interview.

I used semi-structured interviews guided by Van Manen's (1990) framework for interviewing, using the women's personal experience as a starting-point. The essence of the question, said Gadamer (cited in Van Manen, 1984, p.45), is the opening up, and keeping open, of possibilities. I agree with Van Manen that the phenomenological question needs to be clear, understood and also 'lived'. The initial question was broad and open-ended enabling the women to fully describe and reflect their experience of caring for their partners. I opened the interview with the statement: *I am very interested in hearing about the time you cared for..... during his illness. Could you tell me about your experiences?* Van Manen (1990) warns of being too unfocused and it was necessary to have a few prompts. It was necessary to use the prompt I had prepared, which was, *tell me more about that, or, I am interested in hearing more about that.* Looking at the specific aims of the research enabled me to develop a list of possible prompts to encourage ongoing dialogue and "to ensure that similar ground is covered in each interview" (Fielden, 2002, p.75).

- a) *Tell me more about the support you had during this time.*
- b) *Tell me more about your own health during this time.*
- c) *What it was like as the wife/ partner of.....during their illness.*
- d) *What it was like to be the main carer of.....during their illness.*
- e) *Can you tell me your experiences of combining the role of wife and carer*

It was important that I understood the participants' stories and responses and I followed up conversationally by making sure I understood what the participant meant. To do this it was necessary to paraphrase my own understanding of what was said by questioning with the respondent reflectively with the following statement, "Let me see if I understand what you were saying..." (Benner, 1994, p.112).

The interview process took around 1 hour with extra time for setting up and time for coffee usually half way through. There was initial phone contact to familiarise the participant with the process of the interview. The length of time allowed for the interview enabled the women to have a chance to really talk and I was pleased I included extra time for 'cooling down' and closure after intense remembering. I planned to conduct the four interviews over a two-week period but this did not eventuate. I underestimated how difficult it would be getting dates and times that suited everyone. It was a month before all interviews were completed. On reflection it was just as well the interviews were well spaced as I too found the interviews very intense and conducting one interview a week was plenty for me to manage. All interviews were tape recorded then transcribed verbatim. The interviews were transcribed by a transcriber (whose role is further discussed under ethical considerations). The participants were each offered a typed copy of the transcription for verification. Three of the women took these and after one or two alterations to correct or add factual information, they were happy for the information to be used in

the study. These same three also accepted a copy of the tape recording. One woman did not wish to receive either, as she felt she could not revisit the story but she indicated that she was happy for me to use the information gathered.

4.4.2 Observation:

Alongside the interview process I kept a journal and made notes in this immediately after the interviews. I initially planned to use this to make notes recording what I had observed during the interviews. However I also found this was a good vehicle for me to use to express my concerns about the interviews and reflect on the interview process. I noted that after the first interview that I had been quite apprehensive and a little nervous:

I don't usually have any problems talking with people and was surprised that I felt rather anxious. I felt this anxiety passed as the interview progressed. We both had a few nervous giggles. Hopefully this quite "not so normal" situation will not have influenced the information gathered. I suspect it might as I think that the nervousness stymied the conversation at times. This was highlighted when the tape was off; the conversation flowed much more easily without the machine running.

Although all the women assured me they were comfortable recording their stories on tape, without exception all appeared much more relaxed and more information was divulged when the tape was not recording. Another clue that it was not a normal situation was that most of the women openly cried often. I observed two of the women constantly wringing their hanky in their hands:

It was hard not to think this was not easy for her, she cried such a lot and constantly wound her sodden hanky around her fingers. Interesting that Rose (pseudonym) had done this as well. They must think I am such a terrible person putting them through this ordeal.

Despite this all the women said they were happy to join the study and felt they wanted to continue to talk through the tears. I observed the frustration for Marion when she found it difficult to get the words out:

The words didn't come; I felt it was not because she didn't know what to say but that her emotional state stopped the words flowing.

These impressions could not be recorded on tape but I found I recalled many of these observations when I listened to the tapes and read the transcripts at the same time. What I think the field journal highlighted for me, was that the raw transcripts on their own did not reveal the detail that I know existed in the conversation and is so important in phenomenological research. It was important to integrate the extension of the process of interviewing, which involved listening to the tape, reading the transcripts and reflecting on my field journal to get the 'whole picture'. I realised that the journal could be identified as a part of the whole and that all three components in the process needed to be integrated to make transparent the meaning of these women's lived experience. The inclusion of the journal enabled me to integrate descriptions of the participants' actions, facial expressions and posture which are all responses that added meaning to the interpretation. These aspects of being human are integral to nursing and also to my particular interest in conversations that enable accurate and ongoing assessment in a refined way.

4.5 Rigour and trustworthiness

4.5.1 *Credibility*

To ensure the trustworthiness of this research I used the four criteria established by Lincoln and Guba (cited in Gillis & Jackson, 2002). The first criterion is *credibility*. For my study, around the experiences of female partners as carers, one way of ensuring *credibility* was to have the participants actually read the transcript of the interviews for accuracy, and once they had validated the transcript it became the data and could be analysed and the interpretation began. For the phenomenon to have been described correctly and to extract significant phrases and statements from the transcripts it is often necessary to conduct more than one interview. However due to the small scale of this project and the time constraints, a second interview did not take place. I have used direct quotes in the thesis, from the interviews, to verify that the results were in harmony with the participant's experiences. The *credibility* of the study, even though small was important. The time spent carefully gathering and attention to the nuances and detail of each woman's transcript underpinned my process in interpreting the data and was paramount to the outcome. While I recognised this was a hallmark of good science it was not until the project was completed that I truly understood the real treasure in this guideline that "Credibility is enhanced by accurate description of the setting, participants, and events observed" (Gillis & Jackson, 2001, p.216).

4.5.2 *Dependability*

The second criterion for credible research is *dependability*. According to Gillis and Jackson (2002), *dependability* refers to the reliability of the data. They recommend an audit trail be kept. To achieve this I carefully documented the details of the

research process, including the research design, methods and sources of the data, as well as the means by which I arrived at the analysis. The reason for the audit trail is so that “another investigator with similar methodological training, rapport with the participants, and knowledge of the field would make the same observations” (Gillis & Jackson, 2002, p.216). This is also where I believe Heidegger’s perspective reinforces the importance of being-in-the-world; by sharing the background material, readers of this research are free to share and have individual interpretations of the data that collectively can help them to understand the lived-experience of these women.

4.5.3 *Transferability*

The third criterion for authentic research is *transferability*. According to Gillis and Jackson (2002), those reading the study may wish to generalise the study findings to other contexts, populations and environments. I carried out a post data collection literature search to validate research findings. While the research studies that I found were not replicas of this project, similar patterns or themes emerged that triggered valuable insights.

An example of this is the literature search I completed when trying to establish if in fact women are the main carers of their terminally ill partners. Aranda and Hayman-White (2001); Taylor, Seeley and Kajura (1996) and Bergs (2001) all carried out qualitative, phenomenological research around care-giving at home. All three studies were carried out in different countries, in different environments, covered both rural and urban areas, and all three studies included a range of age groups. However all three identified the same pattern; that women provide the majority of home-based care. The studies also revealed another theme, which was the person’s wish to die at home. According to Nelson, (2003) Van Manen refers to *transferability* or the

fittingness of study findings to other settings, populations or contexts as the *phenomenonological nod* or *confirmability*.

4.5.4 *Confirmability*

The fourth and final criterion for good research is *confirmability*. Gillis and Jackson (2002) noted that this criterion is used to test how plausible the data is. Like Heidegger (1927/1962), I argue that it is impossible and indeed unwise to *bracket* my personal experience around the phenomenon under investigation. It is impossible to remain neutral because I am a member of the lifeworld and therefore already part of the study. However, I identified and acknowledged my existing experience, assumptions, pre-understandings and possible biases around the research that made the study more confirmable and therefore more valid.

I am not like others. Thus to the extent that I cannot deny my own experience, I cannot deny that others have experience. Objectivity requires me to recognize and affirm my own experience and the experience of others... experience is there, for all of us, and it cannot be objectively eliminated. (Colaizzi, 1978, p.52)

Adding to this criterion is the role of *reflexivity* in qualitative research. I used *reflexivity* to add relevance and accuracy to the results. Koch and Harrington (1998), Gillis and Jackson (2002), and Guba and Lincoln (2000), define *reflexivity* as the critical thinking that is required by the researcher to examine the interaction of the data analysis and the researcher. Doing this uncovered my views, personal feelings, values, assumptions and thinking. It was necessary to be reflexive, as what was highlighted may have influenced aspects of the research. Decisions such as the methodology chosen, the design of the project and the choice of Colaizzi to analyse the data and Benner and Van Manen's influence to interpret the text, have all been influenced by my philosophy. I am making known my participation in the knowledge that was generated from this study to add to the relevance and accuracy

of the results. This supported the recognition that the major strength of qualitative research is the validity of the data it produces (Gillis & Jackson, 2002, p.220).

4.6 Analysis

I analysed the data by using the first six steps of Colaizzi's (1978) method as a framework.

The first step was to carry out the interviews and collect the descriptions of the women's experiences.

The second step was to have the interviews transcribed.

Colaizzi's next step is to read and re-read the descriptions of the phenomenon; at this stage I included listening over and over to the tapes and reading and re-reading the field journal.

The fourth step is to extract significant phrases and statements from the transcripts that have a bearing on the phenomenon.

The fifth stage involves formulating meaning from the phrases and clustering these into themes.

I used the sixth and final step of Colaizzi's framework, which was to identify the essential structures of the phenomenon and refer back to the transcripts to validate my text.

It is during the fifth and sixth stages that Colaizzi (1978) notes that we leap from what the participant says, to how we interpret what they mean. I was mindful that it was this interpretive stage where it was essential not to lose the connection with the original descriptions of the phenomenon but it was also necessary to illuminate the hidden meanings of the phenomenon that I was researching. Colaizzi (1978) reminded me, as the researcher, to "...go beyond what is given in the original data, and at the same time, stay with it" (p.59). I also used what Heidegger (1927/1962)

calls “the ‘circle’ in understanding” (p.195). This has become known as the hermeneutic circle. When interpreting the data, this metaphor is a way of describing how it is necessary to move between parts and the whole of the data. It is impossible to understand any part of the data until the whole of the data is understood and it is impossible to understand the whole of the data until the parts are understood.

I then commenced the final stage of the research, integrating all the data into a meaningful and exhaustive description of the phenomenon. The confines of the word limit for this thesis placed some constraints on the range of the commentary but not the depth or integrity.

It is at this stage that I was guided by Van Manen (1984, 1990), and Benner (1994), in terms of remaining true to phenomenological writing, as both have been influenced by Heidegger (1927/1962) and they agree that the writing up of the research is part of the intellectual work of the interpretation.

4.7 Writing phenomenological research

4.7.1 Van Manen’s influence

Max van Manen is a Professor in the Faculty of Education at the University of Alberta, Edmonton, Alberta, Canada. Van Manen’s teaching and books have influenced New Zealand and Australian nurses research, particularly since his international lecture tours during the nineties.

In the writing of this thesis the reader will notice that I often use the ‘I’ and ‘we’ form. Van Manen explains the reason for this by saying,

In actual phenomenological descriptions one often notices that the author at times uses the ‘I’ form or the ‘we’ form. This is done not only to enhance evocative value of a truth experienced expressed in this way, but also show that the author recognises both that one’s own experiences are the possible experiences of others and that the experiences of others are the possible experiences of oneself.

Phenomenology always addresses any phenomenon as a possible human experience; this is why phenomenological descriptions have a universal (intersubjective) character. (Van Manen, 1984,p52)

A concern I had before undertaking the writing up of this study was that I lacked the ability to write well enough to make the readers ‘see’ the nature of the experience of being both wife and caregiver in a way that would enrich the readers understanding of these women’s experiences. While Heidegger’s teachings and insights guided my approach to the research, I was guided by van Manen when I began writing about the text. Van Manen suggests that the phenomenological writer looks firstly at what the text says and then how the text speaks (1997). He argues that it is essential to be attentive to the details and makes us aware of the importance of the taken-for-granted (1984). Van Manen encouraged me to use reflective understanding to make possible meanings and the significance of these women’s experiences. Taking heed of these directions to use insightful descriptions, the phenomenological writing in Chapter 7 hopefully gives the reader plausible insight that brings them in more direct contact with the world of these women. Influenced by van Manen, I hoped to make the reader wonder about the experiences and nature of the phenomenon of being both wife and carer in the same way as I do. While not necessarily agreeing with my interpretation I hoped the reader would wonder, be enlightened and deeply question the topic being researched.

4.7.2 Benner: on the use of exemplars in writing up research.

Patricia Benner is a Professor in the Department of Physiological Nursing, University of California, School of Nursing San Francisco, California. Dr Benner is an internationally noted nursing researcher and lecturer.

Benner encourages the use of exemplars to augment the findings of phenomenological research. In this study I have used exemplars to illustrate for the

reader the reasoning and understanding process I undertook during the interpretation phase. Benner argues, "The collection and aggregation of exemplars is central to the interpretative task" (Benner, 1994, p.117).

The exemplars I used in the study uncovered similar aspects, themes and patterns shared by the women in the study. They also highlighted nuances that helped with my evolving understanding of their experiences. However not all exemplars showed similar experiences. To the contrary some demonstrated contrasts. Benner's advice was to go between parts of the text and the whole text looking for ways to develop the interpretation, acknowledging that inconsistencies may be found (1994).

"Though we do not all experience or live in the same worlds, these worlds can be described, talked about, and discovered" (Benner, 1994, p.116). I constantly moved back and forth between the parts and the whole of the texts engaging in cycles of understanding, not understanding, interpreting and critically analysing the stories. Benner expected that the study would reveal "blind spots, mysteries and otherness" At this stage Benner's advice was that "One must not read into the text what is not there" (Benner, 1994, p.xviii). Benner posits that the understanding is more powerful than the explanation (1994) and like Benner I hope the reader is "challenged to consider the power of understanding for becoming more effectively, skilfully, or humanely engaged in practice" (Benner, 1994, p.xv).

In this chapter I have informed the reader of the design of the study, discussing the criteria the women needed to meet to be included in the study and why the interviews took place in their homes. I discussed the research methods of semi-structured interviews and observation. I wrote about the significance of rigour and trustworthiness in phenomenological research and how I ensured my research would

be valid. This chapter also informed the reader of the process that would be used to analyse the data, introducing Colaizzi's, six-step framework and my understanding of the hermeneutic circle. The final part of this chapter was devoted to the influence that Van Manen and Benner had on the writing of the findings.

In chapter 5 I will consider the ethical requirements in the research. The reader is informed about my considerations of the Treaty of Waitangi and other ethical concerns and issues that needed to be addressed before the research could be carried out.

CHAPTER 5

ETHICAL CONSIDERATIONS

Chapter 5 is devoted to outlining the ethical considerations of this study. It is divided into two separate sections; one section covers all ethical issues affecting the study and the other section addresses Treaty of Waitangi considerations. As I did not wish to exclude any Maori women who wished to take part in the research, considerable effort went into finding out the appropriate protocol to ensure all ethical issues were resolved. The path followed is discussed below.

5.1 Treaty of Waitangi

Te Tiriti o Waitangi is a historical document that has contemporary implications which extend to how research is conducted as it describes a relationship between the Crown, acting on behalf of New Zealand people and Maori people based on the principles of partnership, protection and participation. It is because of the authority and regard with which this Treaty is held within New Zealand society that I wished to explore the possibility of not actively excluding any women who identified as being Maori from being participants in this study, either through their perception that the study might not be culturally sensitive to their values and needs or simply that the nature of the study did not reflect their cultural values. While the population of Maori in the area under study was low nonetheless there are always Maori who are cared for in our community. The 2001 census identified that in the local township 7.6% of the population identified as being Maori and in the outlying areas 5.7% identified as being Maori. Similar to Tolich, who identified a concern about exclusion, (2001), I wondered if I would not be promoting the Treaty responsibilities

of partnership and participation, and therefore the right to benefit from this research, if these women were not able to be included. The New Zealand Palliative Care Strategy (2001) identified that: Maori lacked awareness about palliative care; Over half the Maori people who die from cancer die at home; and clinicians do not always work with the wider whanau when providing care, yet the whanau is the main support person for the dying person. The Strategy also recognised that there were no Maori palliative care providers at the time it went to print. Support as to how to evolve my understanding came from Section 4.4 in the Health Research Council (HRC) ethical guidelines that state clearly “ All issues relating to Maori cultural and ethical values should be resolved in discussion with the whanau, hapu or iwi concerned” (Health Research Council Guidelines, 2002, p.24). I sought guidance around this issue by consulting with the umbrella group representing the three local Iwi. I discussed my research with the contact person for the Iwi and she agreed to consult with the group at their next meeting. At this stage it was agreed that it was not necessary for me to attend the meeting but I made it clear I was very willing to discuss the research with the group if they needed further information. The HRC Guidelines for Researchers on Health Research involving Maori, recommend that exclusion of Maori participants, for cultural reasons, from a general population study should only happen if there was a clear recommendation after consultation. If any Maori women agreed to take part in the study I would have actively sought cultural supervision. The Iwi committee agreed to the inclusion of Maori women in the project if any wished to be included. I received a letter of support but have not included this in the appendices, as it would identify the area under study.

One woman identified as Maori but her husband did not. While she acknowledged and approved of my contact with the local Iwi she did not feel I needed to attend cultural supervision. I have not identified this woman to ensure privacy.

5.2 Ethical issues

This research involved human participants and sought to further nursing knowledge by means of in-depth interviews. For this reason the application needed to be submitted to an Ethics Committee. As I am a student at the Victoria University of Wellington, I was required to send an application to the Human Ethics Committee for approval of this research project. As I work for a District Health Board, I was also required to receive approval from the appropriate Ethics Committee. This Ethics Committee is accredited by HRC. They use the National Application Form for ethical approval (form EA 05/02). I have not identified the regional Ethics Committee to ensure the area the research was undertaken cannot be identified. The ethical issues that needed to be dealt with were as follows:

5.2.1 Informed consent

All participants who took part in the research gave their consent. They all received an information sheet (Appendix B) describing the research and by agreeing to take part in the study I believed they consented to being involved. All participants were required to sign the consent form (Appendix E) that was in accordance with the Code of Health & Disability Service Consumer Rights (1993). The key elements of this are that there is sufficient and appropriate information about the study given to the women and that they understood that information.

5.2.2 Voluntary consent

There was no financial reward offered or undue pressure placed on the women to take part in the study. All women knew that they could withdraw from the study anytime before the data analysis took place. As I had been involved with the participants when providing a health service I approached my manager and two team members and asked them to select 8 women who met the criteria for the study. I did not know whom they selected. The manager of the community nursing services in the area sent four women a letter (Appendix A) inviting them to take part in the study. Letters continued to be sent on a rolling basis until four women were recruited. Included in this post out was the information sheet (Appendix B). The women were asked to make contact with the researcher by phone if they were interested in participating. I enlisted the first 4 women who responded to the invitation. At the time of this phone contact I discussed the research to make sure they understood the nature of the research in which they were being invited to participate. Another follow up phone call was made once the women had had time to reflect on their decision to make sure they were still happy to take part. At this time a day and time to meet was arranged. The consent form (Appendix E), was signed at this meeting before the interview process began.

5.2.3 Privacy considerations

All women who took part in the research had their privacy protected as required by The Health Information Privacy Code, 1994, (HIPC). According to the HRC (2002), the HIPC is the starting point when considering any privacy issues around health research. Health information is information about the health of an individual and this form of information comes under the scope of the HIPC. "This includes information concerning: health and disability services provided to an individual" (HRC, 2002,

p.38). As a palliative care service is provided to the family, as well as the patient, the women in this study have been provided with a health service when they were caring for their terminally ill partners. To meet HIPC rules only information necessary for the research was collected. All data collected was stored in a locked filing cabinet that could only be unlocked by myself. All data was accessed only by myself. All tapes were coded with a non-identifier, in this case a number, and the name of the interviewee was stored elsewhere. All tapes were destroyed once the project was completed. All the participants were offered a copy of their interview; three accepted a copy of their audiotape and a copy of their transcript. As previously mentioned one woman did not wish to have a copy of either the tape or the transcript. All participants were given a pseudonym to ensure confidentiality and most identifiable personal details were removed from the transcript that I used. I acknowledged the fact that I knew who the participants were but am entrusted to maintain confidentiality of the participants. The transcripts were destroyed once the project was completed. Material generated on the computer was kept secure by only using my personal computer and having a password to access this. The back-up floppy disc was kept in the locked filing cabinet. The data gathered for this research project was not used for any other purpose. At the completion of the thesis it has been submitted for examination at Victoria University of Wellington. It is also possible that journal articles may be written for publication and the results of the study may be presented at conferences so that what the researcher learned may be shared with others. This has been discussed with the participants. The Ethics Committee reminded me of the importance of the confidentiality and anonymity of the participants in the writing of the thesis.

A transcriber who signed a confidentiality agreement (Appendix D) transcribed all tapes. The information provided was kept confidential to the researcher, the supervisor and the transcriber.

No names were used in the results although permission was sought to use direct quotes.

5.2.4 Risks

One of the risks when this research was undertaken was the fact that it may have been emotionally demanding for both the participants and the researcher. This was indeed the case. I arranged for the local grief support person to be available as a means of follow-up for the participants. I discussed requirements for this service if the need arose and she indicated a sincere willingness to take on this role if required. This person was already known to some of the women through her involvement with The Regional Hospice Trust homecare service in the area. This is a free service. I also identified the possibility that this research could be emotionally challenging for me when I was writing the research proposal. For this reason I decided to attend professional supervision when conducting the study. Initially I planned to do this monthly but I did not feel this was necessary after attending two sessions. I knew that I was able to use a counsellor in the area who was funded by The Regional Hospice Trust and whom I felt comfortable confiding in. I also had the support of a university supervisor during this research project.

I identified possible risks to the transcriber. I wondered if issues might have arisen for her when hearing these women's stories. The transcriber was offered opportunities to discuss any emotional issues with me and if necessary with a counsellor. We talked regularly on the phone and while she admitted to finding some of the stories sad she

was more amazed at what remarkable women they are and she felt privileged hearing their stories.

I considered the possibility that 'bad practice' issues may arise. Every woman was given the written procedure for making a complaint should this arise. (Appendix C.)

5.2.5 Benefits

The benefits for the women in this study may be that the research provided an opportunity for them to tell their story about something that has been very significant in their life. I anticipated these women might be pleased to be involved in research that may contribute to better experiences for other women involved in caring for their terminally ill partners. It was interesting that all of the women did not feel their stories were of great significance and worried that the information they shared would be of no value:

Life was very uneventful apart from what was going on between Sam and me and within these walls really. I feel as though I have perhaps not answered all the things... yes, yes it's a pretty boring story really; it's just your very ordinary story.

After hearing these women's stories I couldn't believe that any one of them could possibly think that their experience was boring and not worthy of exploring.

Niven (2001) noted that her participants commonly expressed a satisfaction around being able to contribute to better experiences for others. She noted that Salakys, (2000) work affirmed this. While the women may have thought their stories didn't yield significant information they all hoped whatever it was I took away from my time with them was helpful for other women in the same situation.

If it helps someone else then yeah.

A benefit of the research itself is that it will enrich our understanding and may be useful in improving quality of life and reducing the social impact by developing and

building on the existing support systems that are already provided to these women. If improvements are required these could reduce the social and psychological consequences of disease on patients and their families. Development of support systems is identified in the HRC Research Portfolio Strategy: Non-communicable diseases (2002-2003, p.70). I consider that any potential benefits from improved health services out-weigh the risks of undertaking this research

5.2.6 Dissemination of results.

The results of this research were written up for a thesis as part of my Master of Art (Applied) Nursing degree through the Graduate School of Nursing and Midwifery at Victoria University of Wellington. Once completed the thesis is lodged in the Victoria University of Wellington Library. While journal articles written for publication in professional journals and conference presentations have already been mentioned perhaps the most important use of the research is with colleagues in practice and in conversations and presentations within the community.

This chapter has discussed the ethical issues that I felt needed addressing and had to be addressed before the Ethics Committee would approve the study. This was a considerable commitment in terms of time but the attention to detail enabled the approval to go through with very little adjustments being made and praise from the committee for the quality of the application.

With the interviews undertaken and the transcripts completed and approved by the respective women, chapter 6 introduces the participants and presents an analysis of the data.

CHAPTER 6

DATA ANALYSIS

6.1 Introduction

Chapter 6 will introduce these four remarkable women to the reader. All four women have been given a pseudonym. By articulating my 'reflective understanding' I hope to give the reader plausible insight to the women's experiences bringing a sense of direct contact with them. This then sets the scene for working phenomenologically with their conversations. In this chapter I will identify the two themes that are the focus of this chapter, responses to health issues and inner strength. These two themes are supported by previous research and my own biases as to what occurs.

Some of the women involved in the study had experienced their partner's illness being extended over a number of years, all the women agreed to make the starting point of their stories from the time that no further curative treatment was offered to their husbands.

As I mentioned in chapter one I have been intrigued with rural women who care for their terminally ill partners, identifying in particular their apparent ability to cope, make do, improvise, self-manage and just get on with the job. I have felt that there was a cost to these women in terms of their own health and quality of life. This chapter explores emotional and physical health issues experienced by the women in this study.

6.2 Four amazing women

6.2.1 Carol

Carol is a lady in her early 60's. She has a grown up family from her first marriage. This lady appeared to be the most stoic and yet her story was perhaps the most tragic. Carol had cared for her invalid husband from her first marriage for a number of years. It was while on honeymoon following her second marriage to David that he took sick and 2 weeks later he was diagnosed with a rare cancer. Carol proceeded to care for him. During this time there were many ups and downs until his inevitable death 8 years later:

[...] I had helped him through a good many rough patches and that probably prepared me a bit for it, but I don't think I really realised what it was going to involve, never thinking it would go on for so long.

6.2.2 Rose

Rose is a lady in her 60's. All her adult children live in the area. Rose said she would like to participate in the study but acknowledged that she would not have done this if it were anyone other than myself undertaking it. She felt comfortable talking to me because of my involvement with her and Graham. When the transcript and copy of the interview was offered for checking Rose declined. She said she was happy for me to use the information but did not feel she could revisit the story again. It had been much more emotional than Rose had anticipated. The suddenness of Graham's illness and subsequent death had obviously been extremely traumatic for Rose:

Everyone was there looking pretty serious and they just said that he had cancer and it was just a matter of time // (Rose very upset).

I said if it's only a matter of weeks, we want quality time and that's what we are going to have and so that's what happened.

6.2.3 Marion

Marion is also in her 60's. At the time of her husband Sam's illness she had 1 adult daughter living nearby but her three other adult children came home. Sam's death was also relatively soon after his diagnosis of cancer. Much of Marion's sadness appeared to be the fact that for what ever reason Sam would not talk about his impending death. Marion said he would not accept the fact he was dying; Marion found this very hard and terribly sad:

He wouldn't speak to him (the priest), Sam was just trying to handle it, and it was terribly sad, it just broke my heart and he was, yeah, he was very angry with me, you know (Marion crying). He never accepted that he was dying really and it made it so hard (Marion crying) and he wouldn't talk to his girls about it, or to me. We wanted to share with him, share his grief; I'm sure it would have helped him. I couldn't pretend everything was all right (Rose very upset).

6.2.4 Wendy

Wendy is another lady in her 60's; she is the most isolated of all the women I interviewed, living 45 kms from the main rural centre. Wendy has 2 adult children in the area and another two who live in New Zealand but visited regularly. Wendy's husband Clive had battled his cancer for some years undergoing a number of operations and treatments. Wendy thought this would continue to happen:

[...] told him he couldn't do any more. [...] because all of this had been going on for quite awhile at this stage and I guess we just thought that, I mean, we were going to keep on having bits out forever and we didn't really think it was going to come to this.

Over the time of entering the homes of women, such as the four in this study, I have suspected that women that care for their terminally ill partners find this an exhausting and often solitary journey. I have often thought that these women must find caring for their partners depressing at times and wondered why the majority of them rarely exhibit noticeable signs of this. Research supports many negative aspects of caring for a family member who is ill (Ayres, 2000; Bergs, 2002; Boland & Sims, 1996; Bull, 2001; Gaynor, 1990; Hinton, 1994; Neufeld & Harrison, 2003; Perreault, Fothergill-Bourbonnais and Fiset, 2004; Ross & Grayton, 1997). It is always possible to find examples of the many problems that affect the carers' life when they are faced with taking on the role of caring for their family member; many of these have been highlighted in chapter two. However a number of the women that I have connected with as a rural palliative care nurse appear to gain pleasure and satisfaction from providing care for their terminally ill husbands. There is however always an underlying sadness about the situation they find themselves in. Knowing they are going to lose their partner and witnessing their husband's deterioration and eventual death is distressing and this distress is quite clearly an ESSENCE or pattern experienced by the majority of women who care for their terminally ill partners. As I began to read and re-read and listen over and over to these women's conversations it was obvious that my assumptions of some impacts and the findings borne out by the pre-study literature search echoed similar themes and patterns experienced by the women. I addressed the findings by identifying the themes of

health issues and inner strength. I looked for patterns that may or may not be the same for each of the women.

6.3 Response to own health issues: mental and physical

It is clear that there were two types of health issues evident, both physical and mental. In this research mental health covered the two emotional issues of depression as sadness, and burden as distress. The area of physical issues looked at the common thread that was clearly woven throughout which was that of self-neglect. For all four women it appeared they were so busy there was little or no time to consider their own health. Given, Given and Kozachik (2001) noted, “most caregivers are plagued by anxiety, depression and caregiver burden” (p.222). They also suggest that evidence indicates that home-care has a greater impact on emotional health. Caregiver depression and burden are more significant than physical health issues.

6.3.1 Depression as sadness

What I discovered hearing these women’s stories was that the four women never talked about actually being depressed but there appeared an overriding impression of sadness. These periods of sadness were acknowledged in phrases such as:

(Marion)[...] and of course you tried not to be depressed so what I would do, I would go into another room and have a good howl.

It was so sad, heartbreaking, you know, it breaks your heart (crying).

(Carol) What hurt him hurt me.

(Wendy) I had a lot of tearful days and I still do at times.

(Rose) I think, I think mentally I just wished the unbearable side away and I just concentrated on positive things, because I couldn't bear to look at the other, so I just sort of did whatever I could, I don't know what it is but for me it was, it was all I could do, I was going to lose my husband, I knew it was a matter of time, so what I wanted to do was to get as much out of that as I could in the time I had (crying).

The sadness expressed by the women highlighted the emotional demands of caring that I have witnessed many carers experiencing. Do we as Scott, Whyler and Grant (2001) suggest, rely on our own personal judgements and intuition to assess carer's needs, focusing more on the physical issues rather than the psychological needs? The information the women shared with me clearly showed that during the final few weeks these women wanted to be with their husbands. Although physically tired they did not want to be parted from them but the sadness of the situation was overwhelming. Witnessing their partner approaching death heralded a range of strong emotions. The four women painted a picture of overwhelming sadness but within that context it was easy to hear other emotions that they experienced. Fear, hopelessness and anxiety were emotions that were expressed throughout the interviews. These emotional responses are predictors of stress. Scott (2001) noted, "The stressfulness of the carer's role in contributing towards meeting palliative care needs of an individual cannot be disputed" (p.324).

6.3.2 Burden as distress

Caregiver burden has been explored in previous research and Given et al (2001) noted, "most caregivers are plagued by caregiver burden" (p.222). Burden in this research is based on Given et al's (2001) definition "Caregiver burden is the distress

that caregivers feel as a result of providing care” (p.221). Nowhere in my interviews with the four women did they mention the burden of caring for their partners but I believe they expressed this in phrases that highlighted the obvious distress of witnessing their partner’s suffering and having to care for them at this time. Carol’s description of her witnessing her partner’s last few hours gives the reader an insight into the distress/burden she endured:

He had those fits that would last three or four hours and that was something I wasn’t prepared for. I always thought he was more likely to go into a coma and never thought of that happening. He just didn’t really come out of them, the noise and standing there holding a wad in his mouth, trying to comfort him and I doubt he could even hear me because he was making so much noise with these fits. It wasn’t something I would ever like to see anyone have to go through, it’s a nightmare that every now and then bounces back at me. It was the most horrible thing I have ever had to do and I was determined to see it through, because he asked me to, and I thought I’m not going to dive out of here and say I can’t take anymore, but I did find it very very hard to stand there and get through those hours. I just think everything, really couldn’t give him much relief and that seemed cruel. So not the sort of thing I would like to go through again. Yeah, it was a shocking day, you know, it just seemed so cruel to me that he had to go through all that, he had been through enough. It would have been easier to accept if he had just gone into a coma, but to have to go that way, fighting to your very last breath. It was one of those horrendous times that I wouldn’t wish anyone to witness or have to go through with a loved one, not a very good time for me.

Much of the literature speaks of the burden of providing care but my observations suggest that burden does not necessarily mean the distress of having to provide care for their husbands but can also be used to express the burden of having to 'see' their husband dying.

Rose's story of Graham's last night is a moving account that expresses the burden she experienced witnessing his death:

That night he was very restless and my daughter had decided to stay that night. He had a ripple mattress and so he was lying on that and I went and lay down on one side of the bed and she was sitting on the chair on the other side. We would change around and have a rest but when I was on the bed he asked me to put my arms around him (Rose crying) and I couldn't, because he was too swollen I couldn't get my arms around him properly. I sat with him and I can't remember but anyhow something happened. I said to him what's the matter and he just looked at me and I said to him, what's the matter! And he mouths," I can't breathe". Anyhow I yelled out to (my daughter) and asked her to come in and she came in and sat with him and I really ran away, I actually ran to ring the doctor and she (daughter) called out and said "Mum he's gone", so I went back and he was holding her hand so tightly she couldn't undo his fingers. From then on I was just numb but I can remember sitting on the bed and holding his head. But for ages I couldn't talk about that, you know I think I ran away, the very time that I should have been there with him, I ran away. (Rose still crying) I still feel really bad that when he really needed me I wasn't there.

I think we can feel the distress and emotion of these women when we read their stories and for some of us it may be possible to experience their distress and share

their burden. Costello (1999) talks of anticipated grief, he argues, “the emotional reactions that take place prior to death may be seen as anticipatory grief”(p.230). The grief of anticipating losing their husbands was evident and for all four women getting used to living without their husbands is still painful. None of the women in this study acknowledged the physical burden of providing care although clearly the physical burden showed itself in the form of tiredness, sore backs and the increased workload. This study supported my observations that despite the obvious physical demands placed on women in the role of caring for their terminally ill partners, rarely do they acknowledge any bitterness, anger or frustration about the role they found themselves in. This does not mean these issues are not present but perhaps rural women have traditionally been able to cope no matter what the cost. The isolation experienced by Wendy highlighted the ‘I can manage’ attitude that all four women exhibited:

(Wendy) I just really had to just figure it out, how to do it and maybe it wasn't the best way. You were basically figuring it out for yourself.

These qualities may well be present in all women caring for their terminally ill partners but my experiences have been limited to rural women and the women in this study were all from a rural area.

6.3.3 Self-neglect

Three of the women experienced physical health issues. These were often put to one side. Given et al (2001) and Burton, Newsom and Schulz (1997) noted, that physical health issues emerge as more care is required, particularly if the care giving time is extended. Wendy and Carol supported their husbands for a number of years throughout their illness and treatment trajectory. These two women suffered the most severe

physical problems and they continued to ignore them. They appeared not to consider their own health important perhaps feeling their health issues were insignificant compared with what their partners were experiencing. Carol's comment bore this out:

I just more or less tuned off to how I felt and got on with the job that I said I'd do. I think that's probably what happened in my mind, I just thought I've got nothing compared to what David's going through, so you just, there were times when my back gave me hang, but I mean it has done that to me for years, so I just got on with the job. I had to go to the GP every three months because of my blood pressure, so I had to go in and have it checked out each three months, sometimes it was up and sometimes it was down, but it still does that, so probably caring for David didn't make it any worse.

Burton et al (1997) also noted that family members who take on the caring role forget to take their prescribed medication. This was evident in a remark made by Marion:

I did absolutely neglect my own health, I didn't take any of my blood pressure pills for about 2 months and for all that, my health stood up quite well but oh, it was a pretty hard time really.

Perhaps the most serious example of self-neglect was something that Carol mentioned when we were having a cup of coffee during a break in the interview. I asked Carol if she would mind telling the following story:

Yeah, well in April before David died I went for a mammogram, which I had been having to have every couple of years or so because I kept getting cysts and they said that I was always

clear. But only about a month after that, I was pretty sure I had a lump but with David getting sicker and sicker it really, it just went to the back of my mind until after he died. About a month after that I thought, I wonder if that lump's still there and the lump was getting bigger. Yes, so it just, yes, I literally put it in the back of my mind and it was more important to be doing for David than worrying about me and that was the start of my round of cancer.

I believe this story resonates with the results of an interview survey undertaken by Rosenman, Le Brocque and Carr (1994) who noted, "caregivers have the potential for exacerbation of existing health problems but by the time treatment can be arranged, serious health problems may have worsened" (p.444).

Carol was happy for me to mention that since then she has had a second lump in her other breast and has now had a double mastectomy.

There is the possibility for the carer to become ill and require medical intervention themselves. Ostwald, Leonard, Choi, Keenan, Hepburn and Aroskar (1993) noted that the physical health of a carer is one of the main factors in determining whether a carer was able to continue in their role as caregiver. Wendy admitted to having high blood pressure before Clive became ill. She said this problem had been off and on if she was under stress but she had not taken blood pressure medication. Wendy's exemplar highlighted how existing health problems have the potential to cause major issues for those in the role of carer if left untreated:

[...] you just put everything on hold and I'll deal with that one later. One night I was sitting in the chair and I felt something dripping down my face and I sort of brushed my face and I was bleeding from the eye. It was a big shock. I didn't know that it was not an uncommon thing. [...] I rang the duty doctor and he reassured me but to come in and have it checked (blood

pressure). My daughter got on my case and when the doctor came to see Clive, he's not my doctor, he insisted on putting me on blood pressure tablets. Even after Clive died, I just couldn't be bothered, I didn't know you were supposed to keep on blood pressure tablets and when they were finished, in fact I don't even think I finished them. I certainly didn't take care of anything that I should have really. I think it caught up with me later.

Clearly Wendy was lucky not have experienced complications from her high blood pressure increasing the likelihood of a hospital admission for herself. I doubt that this possibility ever occurred to Wendy and so the need to look at alternative care for Clive never arose. With home care increasing and limited hospice funding available, hospice at home services require the services of these women and we need to make sure they are emotionally and physically well.

For Rose there did not appear to be any health related issues for her during the time of caring for Graham. This may have been due to the fact that Graham's illness was relatively short and she had good family support and good professional support.

Research suggests that caregivers are more at risk of physical health problems as the demands for increased care extends over time (Given et al, 2001). However it is interesting to note that in an article reporting on a study of 42 family caregivers providing home care to persons with advanced cancer. Aranda and Hayman- White (2001) noted.

Generally speaking, the results of this pilot study do not support the hypothesis that patient dependence and level of symptoms have a negative impact on caregiver anxiety, depression, and fatigue, or that factors increase over time. The results support the idea that personal variables such as anxiety, depression, reactions to caring and perceptions of caring have a greater impact than patient's variables. (Aranda & Hayman-White, 2001, p.306)

In general I agree with this statement but also feel that other variables can affect the carers variables, in particular the amount and quality of informal and professional support.

6.4 Inner strength: total commitment

Exploring this area was of particular interest to me as I have always felt women in this situation seem to manage so well. I often drive great distances to visit patients and living in a beautiful isolated part of New Zealand does not prevent them from experiencing the same health issues as people anywhere else. Often they live in an environment where they only have each other, the empty spaces left by children moving away and communities no longer providing permanent friends and neighbours living at a distance, can often make it difficult to get help and support when needed.

It appeared that all the women were surprised at how they coped and all talked about some form of inner strength taking over. I found this particularly interesting having read Janet Rose's (1990) phenomenological study of women's inner strength. Rose identified an 'essential' that the women in her study revealed that of 'having capacity'. Rose (1990) describes this as the ability to heal, to solve problems, to stay present; to face pain, and to recognise when one does not 'have capacity'. Rose (1990) also noted that the women in her study recognised an ability to continue with an apparent reserve of energy in spite of adversities or disadvantages. This too is recognised as 'having capacity' (p.66). All four women in my study experienced the theme of 'having capacity' and all expressed this directly during the interviews:

(Rose) Well I don't know where it came from, I think I just had this inner strength that just came in and took over. If anyone had said to me before this that this is what you are going to do, I

would have said, no I couldn't do that, but when it, the minute we knew what was happening, I just flipped into a different way, or something. I don't really know what it was but for me it was a total whatever, giving or caring, yeah.

(Marion) It was different to what I thought and I do think the adrenaline helps you keep going. I never got particularly overtired, except on the odd occasion, but not every night. I would go to bed late and get up early and was on the go all the time and yet I didn't sort of feel extra, super tired. Even after Sam died I was still feeling like I was going on adrenaline really, I think, yeah.

(Wendy) I think at the stage where I knew that he wasn't able, I made up my mind that I would do everything to make it as easy as possible no matter what the cost, you know, no matter what I had to give, I would do that.

(Carol) When I left the hospital that night my brother came to me as we were walking out and I said to him as we went out through the hospital door, I said "I walk out of here feeling proud that I gave David everything I could and I don't think I could have done any more." And I did, I walked out of there feeling I had done all that was possible and I didn't think it was humanly possible to have done any more and actually, yes, that was one thing that helped me get through it because I knew that I had done all David had wanted.

However I think all the women had times when they recognised that they did not 'have capacity' and while they did not actually say they couldn't cope at times in their caring experience I feel they expressed this when they said things such as:

(Wendy) My daughter had taken Monday off to be with me because she was worried. I was on the phone and said to him (son) I'm fine, I'm coping, you know. But when I got off the phone she (daughter-in-law) said to him (son) you go home your Mum needs you, how did she know? I did need him, // I did (crying).

(Carol) There were days when it was a struggle and I will admit that and that's often when I gave in and let him have a day or two in hospital just so I could catch up a bit at night time, as long as David didn't blackmail me to bring him back home.

It appears to me that women in this type of caregiving role find an inner strength to cope and deal with the daily demands of caring for their dying partners. They all made caring for their partners their priority and made a commitment to do this. Having a strong relationship myself I wonder if that connection and history are the building blocks that enable women to undertake this challenging role?

In this chapter I have introduced the reader to the four women who agreed to take part in the study. I explored the two themes that presented themselves when examining the transcripts and listening to the conversations. The two themes identified were the women's' responses to health issues and inner strength.

In the following chapter, I look more deeply at the meanings the women have made of intertwining the role of partner and carer. I also examine the role of family support.

CHAPTER 7

THE INTERPRETATION: CARER/PARTNER

**...today, this moment here was the most important part of what we had left,
every moment was important...(Rose)**

In chapter 7 the intertwining of the role of partner and carer is examined and an interpretation of the findings made. While it was not my intention to limit the research to wives caring for their husbands, no unmarried women or lesbian women joined the study. Therefore the experiences of caring for a terminally ill partner in this study are all the experiences of married women.

I have observed the challenges rural women face when caring for their partners. In Scott, Whyler & Grant's study of family carers of people with a life-threatening illness they noted that, "There are many challenges for carers of people with life-threatening illness. Their contribution toward, and experience of caring is an area worthy of investigation" (p.290, 2001).

By looking for the themes I have tried to construct the meaning the women have made of this experience.

This chapter ends by considering the role of family support. During the interview process it became apparent that the role of the family was significant.

It was clear that Rose took on the role of caring for Graham as the most important thing she could do at that time and as we talked I got the impression that looking after Graham was in no way difficult for her. Rose's exemplar highlights the determination all the women in this study exhibited when faced with being both wife and carer of their partner:

In my mind I decided I would be (alright), so it wasn't anything to worry about, forget about that and just get on with today, this moment here was the most important part of what we had left, every moment was important. [...] I really wanted to do it all myself, I wanted to do that. Then I had you there and the other nurses who came every day. That was really important to me because I wanted to do it but I also wanted you there to say, yip, that's right, or do it this way, or do it like that, but as far as I was concerned I would have stood on my head for a week if I had too.

7.1 Intertwining partner/ carer

I have often acknowledged how sad it must be to lose your partner and wondered what it must be like to care for them when they are dying. I have wondered if like Robinson (1990) “the close marital relationship may have served as a form of intimate support” (p.199).

Another statement made by Rose reinforced this view. She talked about her marriage as a partnership. She also highlighted the inclusion of the children as part of the relationship:

(Rose) I think in my mind he had always been the doer and the provider and everything else, meant all of a sudden I could do something for him and I think I actually said that to him once, you know it's my turn now. I think it was like a partnership so what I was doing // (Rose crying) was trying hard to be part of the partnership. I mean, it was just something that was there to do, you know this was what I could do for my partner. So I did it. I also had to be there for the kids as well. Quite often he would say, you'd better do such and such and I would say “for the kids”. I think for both of us we also wanted to make sure that the kids would be all right. You know I was just there for him.

I just concentrated on the positive side and made the most of it and it actually helped him too, I think. Because I think underneath he was worrying about me so I had to show him that it didn't matter, I'd be all right. In my mind I decided I would be (alright) so it wasn't anything to worry about, forget about that and just get on with today and this moment here was the most important part of what we had left, every moment was important, yeah. I didn't want rest, I didn't want anything, I just wanted to be there until I didn't need to be. (crying)

We not I

Of note was the fact that the women often talked about *we* not *I*. Throughout the interviews it was apparent that the women's husbands still play a significant part in their lives and referring to *we* was not unusual:

(Rose) Took me a long time to stop saying, oh well, we this or we that.

I was just there for him

(Marion) I would never go out and leave him, I was lucky that there was always someone here but I rarely went into town at that stage because if I talked to anyone I would get too upset. The kids would do the shopping for me mainly and I didn't want to leave him, I did not want to leave actually leave him in case something happened while I was out.

Irrespective of how the women viewed combining the roles of partner and caregiver the women all experienced multiple role demands. All the women in this study attended to the caring tasks such as bathing or washing, dressing, administering medications, assisting with mobility; for some it required attention to wound care, colostomy care or bowel care. For all four women it involved giving considerable emotional support to their husbands. None of the four women had ever had any

training in attending to the complex needs listed above but not one of them felt they couldn't or wouldn't undertake their partner's care.

I used the three themes that presented themselves when analysing the data to investigate what the women made of this experience. "Themes have phenomenological power when they allow us to proceed with phenomenological descriptions" (Van Manen, 1990, p.90).

The three themes emerged as I explored these women's stories and attempted to make meaning of intertwining the role of partner and caregiver. The first was *whatever he wanted or needed*. The second was the *taken for granted* the third was *intimate support*.

7.1.1 Whatever he wanted and needed: Altruism

While the four women may have expressed themselves individually the impression that I had was that all of them would have done whatever was required to care for their husbands. They all had an overwhelming need or desire to provide whatever was needed and to do whatever their husbands demanded of them. The interesting thing I noted was that none of the women were angry about this, it appeared to be rewarding for them and something they could do in the context of their merging role as carer and wife. While there were times when the women were physically tired the emotional reward was clearly positive:

(Rose) Well the thing was that all of a sudden, you know, I was told this is all (the time) you've got left (together). So in my mind I wanted to make it the best we had, and Graham wanted, he was the same; you know we both said the same. So that's what I gave him, you know, as much, I just gave him all my time you know, that was just as much as I could give him was whatever he wanted you know.

(Carol) I think when they said they could do no more, that just seemed that the bottom had dropped out of your world for a while until you sort of came to terms with it, I made it as easy as I could for him.

(Wendy) If he wanted to do something he wanted to do it then and if it involved me I would just drop things and go and do whatever it was he wanted. I would just walk off and leave everything, just basically whatever (he wanted). One day, it was a nice day, like this, (day of interview) and he decided he wanted to go across to the other side of the bay. We got in the car and went across and when we got there he wanted to come home again, but that was OK, but it took the whole afternoon. One day my brother rang and said they were having a thunderstorm (down the valley). He (Clive) loved thunder and wanted to go down and sit on the beach and hear the thunder and watch the lightening. So we did, just sounds crazy but, yeah, anything he wanted, whatever. If he wanted a special meal, I would get it, whatever I could do and yeah just do it, whatever.

(Marion) I would get up early and I've never needed a lot of sleep. I wouldn't get to sleep until quite late and I was usually tired enough that I would sleep reasonably well, which was a blessing. I'd get up early because I would want to give him his great array of pills early and yeah, it just went from there.

All the women found meaning in being able to give their husbands what they wanted and demanded. Their unselfish concern for their husband's welfare was a

demonstration of pure altruism, where nothing is expected in return and there was no sense of being a martyr.

7.1.2 Taken for granted

During all the interviews the women acknowledged that they all thought their husbands would be there forever. While this impression was not necessarily articulated clearly, all the women gave an overriding impression that they had taken for granted that their husbands would always be around. I found these stories very sad. The women expressed considerable sadness and cried freely as they reflected on the situation. Expectations of how their lives would be and plans that had been made that would no longer eventuate were expressed through their stories:

(Rose)...I would just take for granted he'd always be there and then all of a sudden...

I think in a way I was lucky we went through that. Graham and I we had those few weeks, we got a life time in those few weeks that we hadn't had for a lot of years of our marriage. So even though we had been married for so long those last few weeks were what we would have, you know what I would have liked for the rest of our life, but we did have it, you know, we did actually have that so we were lucky too have that.

(Carol) I think we probably both felt our lives were on hold because when we got married we had so many plans about what we were going to do and none of them eventuated, so yeah it involved both of us, not just me.

(Marion) You know we had been married for a long time and you think about all the things that have happened in your married life, you wish you could have it over again, do things

differently. Not all of them but there is always some things you would like to do differently.

(Wendy) Even though he had radiation treatment, we just pretty much carried on as normal from that point. He went on doing the things he had always done. [...] He had two major projects going. We didn't really talk about anything. [...] No we didn't (talk). We just knew it was out there somewhere and got on with what had to be done. Clive was a very reserved person. It was really hard to bring the subject up with him. I wished now I had pushed it a bit but I just respected he was a person that would tell you in his own time and sometimes that could take a long time but he never got to that point of wanting to talk about it.

Taken-for-granted may seem an unusual theme in making meaning of intertwining both carer and partner but there is an assumption that our own values provide the basis for meaning Farran et al (1991). They further suggest that some values are based on experience.

Experiential values focus on relationships and feelings that persons have toward others. Caregivers' experiential values are expressed as they appreciate relationships with others in their life, and focus on who the care receiver was in the past, while at the same time enjoying the person for who he or she still is. (Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991, p.483)

Reflecting back on the taken for granted enabled the women to express their experiential values. Focusing on their husbands' pasts but at the same time acknowledging the pleasure in being able to care for them suggests that the women found meaning in this experience.

7.1.3 Intimate support

The theme of intimate support was highlighted in a variety of ways. The first area that presented itself was that of the women attending to the intimate tasks of personal care for their husbands. Not one of the women found it difficult to attend to their husbands needs. The importance of communication in a therapeutic relationship is well documented (Benner, 1985,1994). The communication between these women and their partners varied, and although two of the couples spoke openly about their situation the other two did not have the benefit of such openness. However it was interesting to note that the lack of verbal communication around their partner's illness did not prevent these women from providing intimate care and support. These women found ways of providing intimate support and communication in ways other than talking about the situation. Maybe words are not always necessary in a relationship built up by a 'coming-to-know' each other over a number of years:

(Marion) I was very grateful for that (nursing Sam at home) and I can't imagine how I would feel if I had to send him off to hospital. No it was something that I just needed to do for myself really. In a way, I loved looking after him and you did most of that work (nurses). We did a lot during the day (family and Marion) but you (nurses) did a lot there and I was just with him all the time really, so anything that cropped up I did for him. [...] I wanted to be the one to do all the very private stuff that has to be done. Anything that had to be done like that, I wanted to do it but it wasn't for a very long time really, not really.

Marion's story demonstrates the pleasure and meaning she attained in caring for Sam. Intimate support appeared to benefit both the wives and their partners. Seeing their husband's condition deteriorate and witnessing the men they married become so ill and frail was clearly distressing for all the women. I think Carol's account of

David's deterioration highlights the importance of intimate care for both her and David and the sadness experienced as this became more difficult:

(Carol) (As David's condition deteriorated) It was almost like having to turn part of you off and you know that you just can't be selfish about it. David couldn't help the fact that we've got to have separate beds, I mean, I think as you know I pushed the beds together, but there was a gap between. It wasn't the same as being in the same bed and being able to put your hand out or cuddle up in the night and yes, just those little things (Carol missed). Yeah it was as if part of your life had been taken away, yeah, cause like right up until just not that many days before David died, at times when we were going to bed, because I always gave him a cuddle and a kiss as I tucked him down, he'd say, "oh do you think you could get up the edge of the bed and give me a cuddle." You know it was quite awkward at sometimes. I felt so tried sometimes I was scared I would go to sleep while I was there and fall out of bed.

It was not just physical intimacy that was important to the women in this study. Being open to intimate conversation, talking of personal issues and how the illness would progress were important, but not always possible for all the women. Rose's experience of intimate conversations was profound:

(Rose) When we first heard about it (in the hospital), I remember going back to his room and we just talked and talked like we had never talked for years. I don't know what we talked about but it was just like opening the gate. You know that was the beginning, it was like that from then on. I suppose my biggest regret was that we waited until he was so sick until we were able to have that experience because it was beautiful; it really was you know it was lovely.

This was in contrast to Marion and Wendy who both clearly found it difficult that support gained by talking together about what was happening or going to happen was missing:

(Marion) He was always pretty irritable and if we could have talked about things, but I couldn't, he wouldn't. If anyone mentioned anything like what was really happening I don't know what he would have done, he just couldn't handle it at all. His sister came to visit and she said something along those lines and he just about, oh it was terrible, he was so shocked when she said something to the effect that he was dying and I realized that I could never talk to him about it really.

How far does intimate support go? Two of the women, Wendy and Carol talked about euthanasia, both these women had been involved in their partners cancer journey for a number of years. Both women were relieved that they were never put in the position of having to support their partners or family over this decision. This initially came up when I was exploring what it was like seeing your husband change physically:

(Carol) It was in many ways, perhaps like looking after a child a good many times. His moods became pretty childish at times and I used to think, where the hang is that coming from. Often I used to think it's a bit like looking after a child. It wasn't David; he'd changed there. There was another thing, his medication. The amount of medication that was about here and that was one thing that I admired and have often thought of since then, since David died. He never put me under the pressure of saying you've got enough medication just give it to me and let me go. Because of the person he was and the problems he had had in the past with his nerves, I still think, well, I was pretty lucky he

never put that on me. I wouldn't have done it in any case. It was one thing I wouldn't have done for him, I would have done anything but that was one thing I don't believe in. [...] Towards the end, I used to often think about it (David asking) One day he is going to say, "look I've had enough of this." Especially that last month when he was just bed ridden and his bowels weren't working and everything and yeah, I admire the fact that he never ever did ask me to do it, it must, you would have thought, been almost tempting too, cause he knew that there was plenty of medication here (at home) to do it.

Although Marion or Rose never discussed euthanasia, witnessing the deterioration of their once big, handsome and vital husbands was clearly distressing. This may be an area worthy of further investigation. Marion expressed her relief that Sam's illness was not prolonged, this relief was not for herself but for Sam:

(Marion) I think that it was better for Sam to have a shorter time, I think if it had gone on it would have been even more terrible for him. I don't know how he would have handled it had it gone on another three months. He was so, well he just couldn't handle the whole thing at all, men always want to put things right somehow, to see him reduced like that, it's the worse part isn't it? Sam was a person who could always fix a problem - all sorts of problems. He would persist until he found a solution. He was wonderful like that- we were lucky to have him, and we all know that. But this was something he just couldn't fix.

Wendy and Marion may not have had the support of regular in-depth intimate conversations but there were brief moments shared that highlighted the importance of their relations with their partners:

(Marion) One time, early in the morning, I would get up about seven and he had a wheelchair at this stage and I wheeled him out here (lounge). We were sitting looking at the, oh it was winter time and the sun was coming up and he said, this was the only time he ever said anything. He said, "What are we going to do?" like that and I didn't know what to say, I couldn't say "Oh it's going to be alright, don't worry." I just said, "Well, we are just going to do what we have been doing. You have got everybody around you and you've got me." I said "I won't have you when I die." He said, "That's terrible." So suddenly he just thought about it. (Marion crying, unable to carry on).

(Wendy) We got half way down the road the two of us (daughter and Wendy) pushing him in the wheelchair and he made a noise to stop. His voice was really, really weak by that time. I bent down to see what he wanted and all he said was "I love you." [...] We came home again but he wouldn't let me get tea, he just wanted me to sit with him.

It appeared that the two roles merged; combining wife and carer was not seen as two different roles. Looking for the essence of the phenomenon of women caring for their terminally ill partners the essence presented as a double sense, a merging of the roles. The words that appeared that seemed to have significance were *partnership*, *marriage*, *belonging*, *family*, and *we* and *closely joined*, there was an overarching sense of synergy. I think the women found it strange when I asked them to tell me about what it was like being both wife and carer for their husbands. I felt they did not see these as two different roles:

(Wendy) It just felt right, that it should be me looking after him, no doubt about that. I think the two roles just merged really.

The meaning the women found in this experience was the emotional reward, value, usefulness and validation that they experienced. It needs to be acknowledged that these assumptions around the meaning the women in this study made of their experience of intertwining the role of carer and partner, are mine. I agree with Farran et al, "Although general assumptions about finding meaning can be identified, it is important to note that meaning is individually determined. No one can find meaning for someone else" (p.484).

7.2 Support

I looked at the area of support, as it was highlighted when extracting issues or themes found in the transcripts. In the area of support the following themes were revealed: support or lack of it from family and support or lack of it from health professionals.

I decided to cover the role of professional support by looking at the role of the visiting palliative care nurse. This will be discussed in chapter 8.

Family support played a significant role in the experiences of these women, as the family were clearly an integral part of the informal support network.

7.2.1 Family Support: A tower of strength.

(Carol) She hadn't been having a lot to do with me but something must of clicked in (once David became more unwell), yes, she really was a tower of strength to me.

I felt it was appropriate to include family support in this chapter as intertwining the role of carer and partner was also interlinked to that of being a mother and a member

of the family. Of note was the fact that only Carol identified a gap in support received from family members. Carol admitted to not having good relationships with many of David's family before his illness and at times relationships with her own family, most of whom were not in the area were difficult. Neither of David's sons were nearby and visits from them were infrequent. The only family help for Carol came from her daughter, David's stepdaughter. Given et al (2001) found "families that communicated effectively prior to the illness seem to cope more effectively during the illness than those with histories of less functional communication" (p.222). Wendy, Rose and Marion all shared with me positive things about their immediate families i.e.: children and grandchildren involvement. Perhaps Rose's stories best describes the significance of close family relationships at such a sad time:

I think that they all gave their Dad all they could as well you know. For us it was happy times to be together, you know, I mean unfortunately he was sick but it was really good all being together. [...] The family used to look after the meals and things like that; all I had to do was just concentrate purely on Graham and things worked round that. If he needed me I would just go to him, yeah, so my family were always there, they always helped out with the work. We just automatically slipped into a system where everybody helped everyone else.

Rose told me it was not just the domestic chores that the family were involved with but that they gave Graham much loving. She told me how one daughter would massage his back for hours on end; she was able to come in and:

[...] just put her hands on and he'd say "yes 'that's the right place.'" So all of them had special, there were special things

they could give him. She could do his massage and (son) was always there to talk to Graham and he would do whatever things Graham wanted.

Rose said she found it helpful to have the grandchildren around and expressed this in the following lines:

They actually gave him lots of loving energy yeah, so he was able to give it back to them. He adored the grandchildren and they adored him. They would come and talk to him. [...] And yeah they were really important, but as he gradually got sicker, they still came and they were very much part of the link, the life link, the energy link, love link. They actually stopped climbing all over him because he was getting much more frail but they instinctively knew. Graham was sick but it was just another normal day and they were part of that and they were just so much part of his life. I think they knew when to be quiet, when they could relax, they were really good, they were just so neat.

Rose's family all lived nearby and spent more and more time at the family home as Graham's condition deteriorated. Both Wendy and Marion also shared experiences of helpful support from immediate family members. Unfortunately for Carol she did not have this support and she commented on the importance of this near the end of the interview:

(Carol) I think the biggest thing when you are coping with that, is some family support you know. Having the patient's family supporting because it's important to the patient that they get that family support. You know that the family is coming to visit them. So often the family just can't bring themselves to do it. I think it makes it easier for the caregiver too because they see

them (David) fretting because they are not getting family support. That just puts more strain on the caregiver because they have to try and lift them (David) above that, I think that is a very important thing. I just think it is a shame that families don't go and visit and visit right from the beginning and then it is not so hard on them. I think it was a shame his mother was just so awkward and didn't work in, cause she could have spent many happy hours with him. I mean she could have stayed here at different times while I went and did some things, even if it was only down to garden. His brother could of come and sat with him too but he reckoned he couldn't handle it. Some of his close friends, you know he only had one or two really, really close friends and they just wouldn't come and that reduced him to tears many times. You know I think they missed a lot because of that. If they had come right from when we first found out and worked their way through it with him, instead of coming after so many months and there was such a change that they weren't prepared for it. They just couldn't come back and face it and I mean they could have come and had a yarn while I popped off and did something; I get the impression that they think it's going to jump out and get them too.

It was interesting that family support was seen as just as important, if not more important for their husbands than it was for them.

Something I have noticed in my time of entering peoples homes when someone is dying is that extended family members are often less helpful and can cause considerable stress. Some of Carol's story above supported that. Marion made a comment that I have heard other women echo that further support my observations:

(Marion) There were times when his family came down. Two of them came down, his sisters who were very nice. I had to

entertain them and instead of being in there with Sam I was sort of looking after everyone. So when they wanted to come again I just put them off. It seemed rude at the time but I am pleased I did put them off because my whole life was taken up with caring for Sam.

This chapter examined the meaning the women, who took part in the study, made of the experience of intertwining the roles of partner and carer. The three themes of; what ever he wanted, taken-for-granted and intimate support were identified as those that gave meaning to this experience. The chapter concluded with an examination of family support during the time the women cared for their dying partners.

In the following chapter I discuss what it means for me to work as a palliative care nurse and what these conversations have highlighted that may be of value to colleagues. I also discuss the limitations and strengths of the study.

CHAPTER 8

DISCUSSION

This chapter discusses the role of palliative care nurses who choose to become involved and the implications for nurses in clinical practice in the rural setting partnership. Having identified the themes of the lived experience of women caring for their terminally ill partners as a result of the interviews and through the process of dwelling with conversations and reflecting on my own practice, I became aware of areas that I could evolve in my own practice. Because of the specific nature of the women's comments I could begin to understand how their comments could alert nurses who work in palliative care to ways that together, carers and nurses, could refine nursing practice to recognise the unique emotional and physical health these women experience when caring for their terminally ill partners. This chapter reveals that the commentary from the women which indicates quite specifically that the way in which palliative care nurses respond to the needs of these women who are caring for their partners matters, immensely. Their efforts are strengthened through utilising insight, awareness and reflective conversations with the women in the role of caring for their partner. The women and their partners also know that within the hospice framework of care, the partners and family are included during and after the person's death. Within this framework these women are assisted to plan or visualise a way forward and discover through the nurse-led conversations how to engage in the caring partnership and reveal what it is that they recognise as changes in their partner's condition. Nurses need to discover how to converse with and draw on a woman's awareness and value the ways they can plan together. This also makes the journey recognisable, transparent and fit into a framework of care for the dying,

which respects the partner's primary role. The special time when a person is terminally ill and the nature of caring offer conversational times that build mutual capacity that enable nurses and carers to move with the rhythm of changes that occur and make connections when there is so little time actually spent together. The pathway for healing and recovery from loss often include a time for conversations. These conversations often reveal things that people want to reflect on or share, and can include feelings of loss and bereavement; perhaps share concerns which might include, regrets, faults or mistakes. The insights gained in this reflection enable nurses to take a gift from each of the women and build that into the fabric of their practice, revealing how care might evolve in our communities.

The second part of the chapter positions this study, largely based, on one hour conversations with four women who had been in the role of caring for their dying partner, and considers some possible limitations and strengths.

8.1 Role of palliative care nurse

I felt an area of support that was worthy of discussion and was mentioned during the interviews was that offered by the health care providers. Bergs (2002) phenomenological study of women caring for their husbands with COPD reported that wives felt dissatisfied with the lack of support from health care providers. While the level of health care provision was evident during the conversations, all four women had a variety of different experiences in this area. The importance of advice and support provided by health professionals was apparent.

Death is part of life and the palliative care nurse assists those dying in their unique journey. Margi Martin (1994) refers to nurses as *guides*. She believes it is important to have a guide to show those dying how to cross the boundary of life and death "As in birthing so in dying, there is an ebb and flow, a transition through which a person

can be guided” (p.81). This is not referring just to the moment of death but the process of connecting with those with whom the palliative care nurses are involved. It is the building up of the communication, understanding and coming to know one another that construct the therapeutic relationship that guides patients and carers throughout the cancer journey.

While in general all four women were satisfied with the help they received from the palliative care nurse there was an occasional negative story. Not valuing the women’s knowledge and not responding quickly to cries for help are two areas I examined around negative experiences.

8.1.1 Not valuing

(Carol) One of the nurses would never look in my diary, never looked to see what I had put down, which I found quite insulting to be quite truthful. I felt as if, you know when you other ones (other nurses) came in you always looked to see what I had written down and you always wrote some things down. I really felt that when she came in, I put the book out and it was completely ignored as if it wasn’t worthwhile me writing things down. Couldn’t she have put some little thing there? To me it meant a lot. Probably to her it was a lot of nonsense, but to me I felt it was quite important to my day. To see what remarks you ones had made it was probably quite comforting to me, I felt.

It is important that palliative care nurses recognise the isolation many women in this role experience and validate the wisdom and knowledge they provide. Caring for their husbands was an enormous responsibility for these four remarkable women and they were the most essential piece of the jigsaw that all fitted together as their husbands approached death. I suspect that like myself, many palliative care nurses

rely on the information that women provide as part of the holistic care we provide. They are often able to provide detailed information about their partners' symptoms, appointments, mood, fears and worries that they don't necessarily share with other health professionals. Validation of their input is essential.

8.1.2 Cry for help

All of the women acknowledged that there were times when they needed practical help from health professionals. Looking at this area as it related to the palliative care nurse, Wendy's experience of needing help stood out. Being the most isolated of all the women in the study, parts of her story support what I have suspected; that is that because of the distance from base-support, patients symptoms and the treatments offered are not always monitored well enough. I don't believe this is due to not having the knowledge or skills but due to a lack of service provision i.e. it is considered to be too costly in time and resources to provide the ideal amount of support and care to someone living a great distance from the support base. I have highlighted this plight with extracts from Wendy's interview:

When he first went on medication I had uneasy feelings that it wasn't monitored terribly well, but I blame myself more than anyone else because I didn't speak up, I didn't realize until later that things should have been different. He got really agitated and he couldn't sit still, he would vomit with the liquid morphine so they had to give him something to stop the vomiting... the nurse would say to him " have you got any pain?" He would sort of say, "Oh, a bit of a niggle." And they would push it up a bit (the morphine syrup) Every time they increased it, it would all get worse really. Basically he would be walking up and down the driveway at 10 o'clock at night, so then they would give him

haloperidol to calm him down. That didn't really work all that well, I just felt it should have been better somehow.

It is not always easy for the palliative care nurse to provide the ideal monitoring and support. Due to the time constraints caused by excessive travelling to visit a patient, some monitoring and support is offered over the phone. Maybe it is not the best way to communicate with someone requiring help. In their exploratory study Silveira and Winstead-Fry (1997) noted in rural areas caregiver needs are less likely to be met than patient's needs.

The nurse has to rely on the patient's doctor to prescribe the appropriate medications. There are occasions when an isolated pharmacy may not stock the prescribed medication so delays can be experienced before medication arrives:

The day before he died was very distressing, he developed that rattly cough that someone referred to as the "dying rattle" and we all struggled with that, it was wicked. ... The nurse came and we asked her to do something about it. She was a bit hesitant and said "people don't usually do anything about it." ... Anyway we asked the nurse to do something about it and she said there was a drug they could use but she would have to get the doctor to prescribe it. The doctor came out in the evening (without the drug). (the nurse phoned) She said the drug had been prescribed but they (pharmacy) didn't have it in stock and they were trying to get something else. He (my son) was so upset he yelled at her and said "Well get it!" ... I went outside and thought this just dreadful; my kids are going to think euthanasia a good thing because of this.

It is easy for nurses to become so familiar with the tasks of caring that we may expect carers to be able to attend to and deal with activities of daily living that we take for granted. Assistance and education can mean the difference between coping and not coping. Being sensitive, thoughtful and making time to engage with those taking on the role of carer is in my view an essential part of the care provided by the palliative care nurse:

I did ask one of the nurses to show me (how to lift) and she said she would do it next time and I don't think it really ever happened and I just really had to just figure it out how to do it and maybe I didn't do it the best way.

Getting him in and out of the wheelchair and in and out of bed, I struggled with that. I've got a bad back and I really didn't know how to do it, I just had to work it out for myself really, the best way of doing it. I could of really done with some help on that one.

The thing that I found really difficult was shaving him, I really struggled with that one and I got a little bit frustrated with the nurses. I actually said to them that it was really hard and I didn't know how to do it.

8.1.3 Practical help

The women in this study saw the provision of equipment and practical support such as home help and assistance with personal care as invaluable. These provisions have long been recognised as part of the palliative care service. We have to hope that as funding issues become more acute these services can still be supplied.

All the women echoed Marion's account of the practical help. When Marion talks of 'you' she is referring to the nurses in our community service:

(Marion) I thought the help you gave was just amazing and you cheered him up no end.

I think the support we had was wonderful. I know the support you gave and you supplied all the bits and pieces, the towels. You know I never thought of that, I mean I thought we had lots of towels and things but when it comes to something like that you don't realize how much stuff you use. You know you supplied all sorts of little things, and they were washed and laundered and all that. No, that was amazing.

You arranged for the blocks to go on his bed, which made it much easier to get him out of bed, and the wheelchair when he needed it, which was very useful. For the last part that bed from the hospital, there were things like that that were very helpful. I thought it was great the support you gave us in that respect. You made it comparatively easy to look after him.

I know that I could have asked you anything I wanted to know. We got Sam into that single bed, the electronically operated one from the hospital which you organized, really that was the last few days, that was very helpful and he liked it.

8.1.4 Emotional support

Feeling emotional pain during the time the women cared for their partners was clearly expressed during the interviews. The trigger of the interview appeared to bring back all the feelings and emotion the women experienced at the time and I believe their perception of these events is the central tenet of the study. Even as time has passed all the women were struggling to deal with the emotional pain of losing

their partner. However while they all acknowledged that life had changed it had not ended either.

Costello's (1999) ethnographic research project on anticipatory grief explored the role of the nurse in providing support. Costello argues, "Giving emotional support is a key component of the nurse's role in anticipatory grief experiences as well as post-death bereavement." (p.230). I believe all the women acknowledged the importance of the emotional support provided by the visiting palliative care nurse. The following exemplars highlight this:

(Marion) It was the nursing that was so wonderful and that's what you seem to need much more than doctors. You were so good; you (nurses) were just marvellous. The nursing was absolutely marvellous.

(Carol) You know if it hadn't been for the wonderful support from you ones (nurses), it would have been a damn sight harder. What I enjoyed was having that diary that was written in every day. Often one of you would put, you are doing a wonderful job. Little things like that, to me were great, because I really wasn't getting that from anywhere else.

8.2 Practice assessment

If the research I have undertaken does no more than highlight the need for nurses to undertake a much more in-depth assessment of those caring for their loved one in a home setting, then it will have been worth it. This assessment of carers in a home setting is essential for the provision of good quality care outcomes that assist the person dying. A key component of that quality outcome is that we assess the support needs of the carer independently from the patient. I believe it is also important to

have knowledge of the relationship between the person being cared for and the carer.

Nolan, Grant and Ellis (1990) noted the following in their quantitative data analysis.

Such knowledge is unlikely to be gained from a cursory assessment but requires a degree of trust between carer, dependant and the service provider. Such trust is best established where there is a sharing of tasks and regular contact between all parties. Given the high dependency and levels of disability with which many carers are faced, this places nurses in the unique position of providing care of an often very personal nature to the dependant, whilst also having the professional knowledge and expertise to give the carer advice, support and training. (p.552)

It is important that we, as visiting palliative care nurses, don't think that because on the surface these women appear to be coping and managing, that we can neglect the assessment and provision of appropriate physical and emotional support. In a study of 207 carers in Britain, Jones, Hansford and Fiske (1993) interviewed principal carers two to four months after the death of the loved one they were caring for. The participants were asked about what happened in the four weeks before the death. Most carers said they experienced physical symptoms but they were reluctant to mention these to the doctor, as their own problems didn't seem bad enough to bother the doctor with. More noteworthy was that the carers felt that the doctors and nurses would ask about their own problems if they were important. "Clearly many carers believe that doctors and nurses would know about their problems without being told" (p.4). Equally this could suggest that carers expect health professionals to know that they are experiencing emotional issues. Jones et al (1993) felt that this kind of deficit lies with the health professionals and the challenge is to encourage colleagues to practise patient-centred care. Reminding us that palliative care encompasses the support of family, whanau and friends who look after someone who is dying.

8.3 Limitations and strengths of this study

In this second section in the discussion it is important to recognise that while each woman offered her unique experience of caring for her partner, their comments touched a broad spectrum of interests and concerns for me as a palliative care nurse. It is important therefore to offer some comments on the limitations that exist in the study while balancing this with the obvious important strengths. Phenomenological research comes under the heading of qualitative research.

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that exposes a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting. (Creswell, 1998, p.15)

Use of hermeneutic phenomenology in nursing research can provide a rich source of knowledge around understanding the lived-experience but is often criticised for its limitations (Crotty, 1998). Wilkie (1997) noted that because investigators often work with smaller numbers it could make it difficult to have the study accepted as a rigorous and scientifically valid piece of work. The numbers in this study may have been limited to four but they were all committed to sharing their experiences. When researching the lived experience someone has had to experience that phenomenon and the number of participants is less important than the “uniqueness of participants’ human health experiences”(Gillis & Jackson, 2002,p.220).

The major strength of qualitative research is the validity of the data it produces. Because researchers collect data by means of in-depth interviews and participant observation in natural settings, the participant’s true reality is more likely to be reflected in the rich descriptions that result than would be reflected in data collected in contrived settings using qualitative instruments. (Gilles & Jackson, 2002, p.220)

While the number of participants may be small every one involved in the study experienced the phenomenon. This way the data is specific to those studied as opposed to the use of random sampling of quantitative research.

This study was limited to the examination of four married, rural women who experienced caring for their terminally ill partners who subsequently died. Because the number of participants was small the comments are unique and may not necessarily be generalised to other carers. The women wanted to point out certain ways to improve services and help others by sharing both positive and negative areas of the service and their experiences.

I suspect the study may be limited by me as the researcher. Sandelowski (1997) stated that “Qualitative research seems warm and fuzzy next to the demands of statistical work and therefore draws to it’s ranks persons without the requisite training, talent and skills”(p.127). Never having undertaken research of any kind I admit I felt and still do feel that I may fit into this category. I attempted to overcome this by adhering to the criteria that Reason (1996) (cited in Sandelowski 1997) suggests qualitative researchers embrace. Researchers need to “face the people”, “interrupt patterns of power” “speak and write in a manner that makes people think”, “heal our worldview,” and ultimately, “to be of use”(p.127). Through the research I have endeavoured to meet these goals and therefore make the inquiry resemble actual life as it was for these women and allow us to see their reality.

The particular strength of this study is the description of the experiences seen in the exemplars. I believe another major strength of the study is that it was undertaken in rural New Zealand and is therefore particularly relevant to the provision of palliative care services in this country.

CHAPTER 9

CONCLUSION

This final chapter considers what the research might contribute to the literature. While I discovered there was international research on carers in rural settings and rural nursing, I was unable to find any published in New Zealand to date. Writing this thesis makes me realise the importance of taking time to reflect on the conversations shared by women in a caring role. I am reminded of the importance of women in the role of primary carer being 100% involved and this takes considerable effort. The work of care forces us to grow as human beings in ways we can never imagine. Conversations take time and I believe they develop as we come to know each other. The trivial chats about the weather, fishing and the dogs give way to more in-depth and intimate conversations of worries, concerns and fears. Nurses need to take time to listen and not just converse with a series of closed questions to acquire nursing information. What is needed is the information that is shared with and by the primary care giver and the palliative care nurse. By doing this the carer knows what is happening and is supported. The carer also begins to build up confidence and trust with the nurse and is more likely to share their own concerns and worries. Using the nurse as the main support person can be demanding and providing this level of support requires support for the nurses. Issues of time out, supervision and training for nurses needs to be addressed further.

9.1 Key Points ‘Women’s words’

Do we make the difference we think we do or do rural women caring for their terminally ill manage largely without significant help of formal services?

One of the most frustrating problems I have encountered is the all too common problem of patients not being referred to the palliative care service. We frequently hear in the community of someone who is extremely ill and a carer who is struggling to cope. I suspect this is not only a problem in rural areas; in fact in a relatively small community, friends and family of those struggling often ring to see how they can access help and services. Grande, Todd and Barclay (1997) suggest, that the accessing of services and timely introduction to palliative care services are essential for ensuring adequate home care support. All the women in the study had been part of the palliative care service in the area as this was one of the criteria for entry into the study. Further research on carers who did not access available palliative care services may be of value.

I stated that the rural women in this study demonstrated an ability to cope, make do, improvise, self-manage and just get on with the job. It appears to me that self-care is implicit, however in this study the women did not notice that perhaps they neglected their self-care. This was not deliberate, but that is common when women are faced with caring for their terminally ill partners and they turn their full attention to their dual role of partner and carer. The women in this study indicated that they missed the role of being just a partner.

Three of the women in the study neglected their own physical health and emotionally all four women’s responses were of overwhelming sadness as they witnessed the approaching death of their husbands. The study revealed that none of the women in the rural area I practice identified having to provide their partner’s care a burden.

However they all expressed the burden of having to 'see' their husband dying. The importance of their own needs and health were seen as not important compared to the issues their partners were experiencing.

All four women exhibited an 'I can manage attitude' and all talked of some form of inner strength taking over to deal with the demands of the position they found themselves in.

Rural women in the study all found meaning in their need and desire to care for their husbands. This meaning was identified by the positive emotional reward they experienced as they intertwined the role of partner and carer. Of note was the fact that these rural women felt that being both wife and carer for their husbands was not two different roles. The dual roles merged, the marriage was seen as a partnership and 'we' not 'I' was important.

An interesting finding in this study was the significant role of family support and the importance of this in rural practice.

The role of the palliative care nurse was identified as an integral part of the support needed when caring for their partner. Practical and emotional support were both seen as vitally important.

The study identified similar themes experienced by carers globally and reinforces the value of women who care for their terminally ill partners.

9.2 Policy Guidelines

As a result of this study I am reminded of the importance of education for those who work in the area of palliative care. The New Zealand Palliative Care Strategy, 2001 recommends the education of health professionals and volunteers that facilitates appropriate care for those dying (p.23). The Strategy covers the area of workforce and education in relation to nurses and doctors, recommending the development of

these requirements. It even discusses the ongoing training for volunteers (p.19).

However it appears that the requirements of the main caregiver have failed to be addressed.

The women who provide care for their dying partners do this on a voluntary basis and they require some education to carry out this role. The palliative care nurse should provide that education. I believe this is an essential part of the service provided and extra time is required to do this properly.

The vision for the provision of palliative care services in New Zealand is that: “*All people who are dying and their family/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*” (p.7). Of interest is that the Strategy further states that:

Underpinning the vision is a community model of palliative care services. This means that palliative care services should be provided for most dying people and their families/whanau in their own home, where this is their wish. The vision also assumes that the family/whanau will be active in assisting with care where this is appropriate. (NZPCS,2001, p.7)

Research supports the person’s choice to die a home (NZPCS, 2001, p.6). If we are going to rely on family to provide the majority of care in a home setting then it is essential that their needs and health are assessed independently. It appears that this area has not been addressed sufficiently in the NZPCS, (2001).

9.3 Concluding statement

This study arose from my intrigue with the number of women who care for their dying partners in the rural area where I live and work as a district nurse providing community palliative care. This interest has put me on the learning path and at times I wonder where it will end. Palliative care is the area of practice I particularly enjoy

and it is in this area of nursing that I have worked to develop my knowledge and skills. Each step has opened another door, revealing a new space that needs exploring. This exploring has made me look at my thoughts, feelings, actions and decisions in relation to my practice. Simple tools such as reflection and critical thinking are available to us all and help us to gain nursing knowledge and improve practice. I believe my increasing knowledge reinforces my commitment to providing the best care I can. Education has enabled me to develop and extend my practice, especially around the area of conversation with a person who is dying and their family. It has reinforced the need for me to weave my personal and professional self together. I feel lucky to realise very early on in my nursing that I could accept and deal with the 'tasks' of nursing but the enjoyment came from truly caring about people and spending that extra time, that momentary human to human exchange or touch that shifts emotions, or moves something along or simply changes the day from awful to hopeful. For me when caring for terminally ill patients and those close to them it is essential to have built up a relationship that is brought about by knowing each other. I believe that expression of caring is what has shaped my practice over the years. I believe we are all individuals and our own life experiences and personality have an enormous impact on our behaviour. My practice has been influenced by my values, my unique life and my nursing experiences. These things will be different for each one of us. This study has reminded me that we are all individuals and we all find our own ways of coping. For me to continue in my role as a palliative care nurse I also need to self-care. I attend to this by, spending time with my family. I don't believe I could practice as I do if I was going home at the end of an often long, emotionally draining day to a difficult and unhappy home life. My love of nature and gardening, being an ordinary human, and love and care of the

local community are important to who I am as a person. Recognising that I too am an individual and it is important for me to be myself, remind me that this is the best of what I can do.

Expanded practice demands expertise and increased knowledge. These factors enable me, the palliative care nurse, to be more confident in my abilities and have allowed me to develop confidence to advocate for patients and families.

The study has reinforced the need for good communication in the therapeutic relationship and highlights the importance of effective listening. It also reminds me that while I am always professional it is the human-to-human or personal connection that I consider gets us through the tough times of loss.

My exploration of the hermeneutic paradigm facilitated the interpretation of the women's narratives and my own experiences. I found that establishing the links between my own philosophy and the hermeneutic and phenomenological writers supported and grounded my own thinking. It also offered a real sense of being on the right track, in the heart of my own practice.

This phenomenological research does not however provide finite answers but adds to a body of existing knowledge. The following quote is pinned to the notice board in my managers office and is a reminder that answers are not always found:

There is no answer

There never has been an answer

There never will be an answer

That's the answer

Gertrude Stein

APPENDICES

APPENDIX A Letter of invitation to participants

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APPENDIX C 1: Complaints procedure

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APPENDIX A Letter of invitation to participants

The District Health Board letterhead has been removed to help ensure the area is not identified.

Dear

Hello. You are being contacted to see if you would be interested in taking part in a research study.

The purpose of the study is to try to gain a better understanding of your experiences when you cared for while he was ill and dying. Research supports the fact that women are the main carers of those who are terminally ill and that they provide the majority of care in a home base setting. The study is therefore interested in examining the concerns and issues raised by you. Of particular interest is how you managed the role of being both wife (partner) and carer. While this is a very sensitive topic, hearing your stories may enrich health professionals' knowledge and assist with planning and provision of the most meaningful and helpful services for women facing a similar situation.

Karen Campbell is the researcher. Karen doesn't know that you have been approached. Karen is a Registered Nurse and is in her final year as a Master of Arts (Applied) Nursing student, at the Graduate School of Nursing and Midwifery: Victoria University of Wellington. The research Karen is planning to undertake is part of her academic study.

An information sheet is attached to this letter to answer some of the questions you may have.

You are in no way obligated to participate in this study. However, if you do decide to take part, your experiences and input will be greatly appreciated and valued.

Yours sincerely,

Unit Manager

APPENDIX B Information sheet for participants

INFORMATION SHEET FOR PARTICIPANTS

STUDY: Rural women's experience of caring for their terminally ill partners.

You have been invited to take part in this study. Before you make a decision whether or not to participate here is some information that may help you decide.

Who will do the research?

The researcher is Karen Campbell a registered nurse who works in Karen may already be known to you. As part of Karen's study through The Graduate School of Nursing and Midwifery at Victoria University of Wellington, she is required to undertake a research project to complete her Masters degree. Through out the study a member of the academic staff of the Graduate School of Nursing and Midwifery will supervise her. For the purposes of this information sheet from now on Karen will be referred to as the researcher.

This study has the approval of the Human Ethics Committee at Victoria University of Wellington and the approval of the Ethics Committee both of which are accredited by the New Zealand Health Research Council Ethics Committee.

The Study:

The purpose of the study is to gain a better understanding of the experiences of rural women who have cared for their terminally ill partner and who used the district/palliative care services in Terminally ill means that the person's illness no longer responds to curative treatment. Palliative care is the type of care given to those whose disease no longer responds to curative treatment. Palliative care is holistic care and includes not only control of pain and other distressing physical symptoms but also social and spiritual care with the goal of having the best quality of life possible for the person who is ill and their family. Because you are 'family' and the person who cared for their partner, the researcher is keen to hear your story. Of particular interest is what it was like being both partner/wife and carer. By honouring your stories the researcher hopes to enrich nurses understandings of your unique experience. This research may inform efforts to improve the care and services provided to rural women when faced with caring for their dying partner.

Taking Part:

If you are still interested in taking part in the study your involvement would be as follows:

The researcher will talk with you on the phone to discuss the study and its objectives. The researcher will talk through this information sheet and clarify and answer any queries or questions you have. The researcher will also discuss informed consent. You will not be expected to sign a consent form at this stage. The researcher will phone 2-3 days later, once you have had time to reflect, to check that you still agree to take

part in the study. If you agree to take part a date and time will be arranged to meet. The researcher suggests your own home, if that is agreeable. If you would feel more comfortable in another setting this can be arranged. At this interview a consent form agreeing to take part in the study will need to be signed and you will need to verbally agree to participate in the study. The interview can then proceed. The interview is expected to take anything from 2-3 hours. There will not be a long list of questions, but will be guided by your experiences. The researcher plans to audiotape this interview; these tapes will be transcribed by a transcriber who will sign a confidentiality agreement. You will be given a copy of the audiotape for your own use and it also enables you to verify the accuracy of the transcription.

Your Rights:

You do not have to take part in this study. You can refuse to answer any question or choose not to talk about any aspect of your experiences you do not feel comfortable sharing. You can leave the study at any time up until the completion of the interview and you have received a copy of the transcript. Interview times dates and places will be arranged to suit you. You can ask for any parts of the interview not to be recorded on the audiotape, or any sections to be deleted.

It will not be possible to identify you in any reports that are prepared from this study. All those taking part in the study will have a pseudonym. Any information provided to the researcher can be given with the assurance that it will be kept completely confidential.

You may have someone present at the interview. You can ask any questions about the research during your participation.

A summary of the findings of the study will be given to you if you would like them.

As part of the writing up of the research direct quotes will be used. It is your stories that are significant and make the research meaningful. You need to be comfortable knowing that others will see what you say. Remembering they will not know who you are.

If you have any concerns regarding this study you can contact the ethics committee of Victoria University of Wellington or the researcher's supervisor, Dr Margi Martin, senior lecturer, Graduate School of Nursing and Midwifery, Victoria University of Wellington.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate on 0800 377 766.

If you identify as Maori the researcher would like you to know that she has consulted with Manawhenua who have given their approval to the research. The researcher has also expressed that she will undertake cultural supervision.

Use of the Information from this Study:

Results and information from this study will contribute towards Karen's thesis of the researcher. It will be lodged in the library of Victoria University of Wellington. It is possible that one or two journal articles may be written for publication and the study

may be presented at conferences so that what the researcher learns may be shared with others. The research will enrich nursings understanding of your experiences. If the research clearly highlights any weakness in the service provided to women who care for their dying partner, results might be used to advocate for the necessary changes. You can be reassured the thesis and presentations will be presented in a way which will ensure you are not able to be identified, including in the *area*. The researcher will keep all audiotapes and written data in a locked filing cabinet. All audiotapes, computer disks and transcriptions will be destroyed once they are no longer needed. You can request to have your audiotape interview returned to you.

Support if the research causes any stress:

If you feel you need to talk through any feelings, memories, sadness or thoughts that the research highlights you can access *area* a person trained in grief and loss support in *area*. The researcher will provide you with details if you need this service. Similar types of study show that most participants find that sensitive studies provide the opportunity to tell your story and reflect on something that has been extremely significant in your life.

Number of participants:

This research is interested in obtaining rich, in-depth material and because of the amount of information it is expected each participant will provide the number of participants is limited to four. If you are interested in taking part you are asked to contact: Karen Campbell on 525 9737.

For any further questions regarding the study contact the researcher.

APPENDIX C

1: Complaints procedure

2: Grief Support

3: Supervisor detail

COMPLAINTS PROCEDURE

If any concerns or complaints should arise as part of this study in relation to the services you received during..... illness these should be discussed in the first instance with the Health Services manager,

If you do not wish to discuss the issue at this level you may contact the District Health Boards complaint co-ordinator by phoning 03 5461800 and asking for Judy Williams.

If you are not satisfied with this process you may wish to contact:
ADVOCACY SOUTH ISLAND: 03 544 4116 Freephone: 0800 377 766

GRIEF SUPPORT

If you need to talk through any feelings, thoughts, memories or sadness you can contact is a support person for grief and loss in

..... She maybe known to you through her involvement with the Nelson Regional Hospice Trust homecare service in This service is free.

UNIVERSITY SUPERVISOR DETAILS

If you have any concerns about this research you can contact the researcher's university supervisor.

Dr. Margi Martin
Graduate School of Nursing and Midwifery
Victoria University of Wellington
Wellington
Ph: 04 463 6140
Fax: 04 463 5442
Freephone: 0800 108 005
Email: Margaret.Martin@staff.vuw.ac.nz

APPENDIX D Transcriber confidentiality agreement

Transcriber confidentiality agreement

To ensure confidentiality for the women whose interviews I will be privy
to, I of.....

state that I will not divulge any information in the transcripts I produce
for the researcher Karen Campbell.

Signature.....

Date

Thank you for signing this agreement.

Signature.....

Date

Karen Campbell
Researcher

APPENDIX E Consent form

CONSENT FORM

STUDY: Rural women's experience of caring for their terminally ill partners

CONSENT TO PARTICIPATE IN RESEARCH

I have been given information about this study in both written and verbal form.

I have had the opportunity to discuss this study with the researcher. I have had time to consider whether to participate. My questions regarding the study have been answered to my satisfaction.

I understand that I will be asked to talk about my experiences of caring for my partner when they were terminally ill.

I understand that I may withdraw from the study and /or withdraw any information provided up until the transcript has been read. I am aware that unless I request otherwise I will receive a copy of the transcript to ensure accuracy and indicate if there are any areas I would not like revealed for privacy reasons.

I agree to provide information to the researcher on the understanding that it is confidential and that all my information/data will be kept secure. I understand that I can request the audiotapes of the interviews will be returned to me at the end of the project.

I have been given a copy of the information sheet and consent form and agree to participate in the study under the conditions set out on the information sheet.

I consent to the interview being audio taped.

I agree to my interview being transcribed and understand that the transcriber has signed a confidentiality agreement.

I know whom to contact if I have any concerns regarding this study and am aware that the study has ethical approval.

I understand that to keep my participation in this study confidential I will be given a pseudonym. I know that any information that enables me to be identified will be removed. I also know that although the research will be carried out in the area will not be identified.

I give my permission to use direct quotes from my interview and am aware these may be used not only in this study but also in related articles and presentations.

I know how to access grief and loss support should I require this service.

I understand I will be informed when the thesis is available to be read.

I _____ hereby consent to take part in
this study.

Signed: _____

Name _____

Date: _____

Researcher: _____

Signed: _____

Date: _____

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